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ABSTRACT

This hearing relates to the provision of assistive technology devices and services for disabled individuals, focusing on the need for a coordinated federal effort to assist states in the provision of these services. Proposed legislation (S. 1586, the Technology to Educate Children with Handicaps Act, called TECH Act) would establish assistive device and technology resource centers nationwide. The centers would assess the needs of handicapped children and train specialists to assess their needs and to determine the most apppropriate assistive device. The centers would help find funding for devices; train parents, educators, and children in how to use assistive devices; and disseminate information. The hearing transcript contains presentations and prepared statements from: (1) Senators Orrin Hatch and John Kerry; (2) representatives from private organizations such as Self Help for the Hard of Hearing, Electronic Industries Foundation, and American Society of Mechanical Engineers; (3) individuals with disabilities, including Teddy Pendergrass, Ann Cope, and Daryl Smith; (4) representatives from the business sector, including Apple Computer, UNISYS Corporation, Champion International Corporation, and Bell Atlantic Corporation; (5) representatives from government agencies such as the Office of Special Education and Rehabilitative Services and the Office of Technology Assessment; and (6) representatives from colleges and universities. (JDD)

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ASSISTIVE TECHNOLOGY FOR PERSONS WITH DISABILITIES

HEARINGS

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

TO PROVIDE FINANCIAL ASSISTANCE UNDER THE EDUCATION OF THE HANDICAPPED ACT TO ASSIST SEVERELY HANDICAPPED INFANTS, CHILDREN, AND YOUTH TO IMPROVE THEIR EDUCATIONAL OPPORTUNITIES THROUGH THE USE OF ASSISTIVE DEVICE RESOURCE CENTERS, AND FOR OTHER PURPOSES

MAY 19 AND 20, 1988

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ASSISTIVE TECHNOLOGY FOR PERSONS WITH DISABILITIES

THURSDAY, MAY 19, 1988

U.S. SENATE,
SUBCOMMITTEE ON THE HANDICAPPED,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The subcommittee met, pursuant to call, at 9:39 a.m., in room SD-430 of the Dirksen Senate Office Building, Senator Tom Harkin (chairman of the subcommittee) presiding.

Present: Senators Harkin, Metzenbaum, Stafford, and Hatch.

Also present: Senator Kerry.

OPENING STATEMENT OF SENATOR HARKIN

Senator HARKIN. Good morning, and welcome to the first of two days of hearings about the role that assistive technology devices and services can play in enhancing opportunities for people with disabilities.

In a nutshell, assistive technology devices are devices used by people with disabilities to assist them in performing an activity that a non-disabled person can perform without the device.

Examples of devices include a specially adapted lift that helps a farmer into his tractor, and a computer that augments a person's speech.

Several witnesses will testify about the essential role that assistive technology plays in their lives. One is Denny Theesfield, a farmer from Armstrong, Iowa.

Denny is a disabled veteran. When he returned to his family farm after losing the use of his legs in Vietnam, he faced the tragic prospect that his disability would prevent him from working on his family farm, a farm that had been in his family for over 70 years.

But Denny, with the help of his family, designed and built a specially adapted lift that enabled Denny to mount and operate his tractor. Today Denny is carrying on the family tradition of earning a living by farming.

The second witness is Teddy Pendergrass, the popular singer, songwriter, and record producer. Teddy was severely disabled six years ago this spring. Having lost most of the use of his hands, Teddy's prospects to continue to write and produce were grim.

But with the help of his vocational rehabilitation counselor, Dennis Turner, Teddy learned how to make use of an assistive technology device that Denny designed. And now Teddy is back at work.

Denny and Teddy are but two of the thousands of examples of people who are employed today because of the availability of assistive technology. But employment is not the only major life activity where technology can make a difference.

Assistive technology also can help individuals of all ages, and in all areas of life, including recreation, education, independent living, and other community activities.

Unfortunately, the promise of assistive technology is not a reality for tens of thousands more disabled Americans whose potentials remain untapped, who remain in institutions or inappropriate placements, or who are unemployed or underemployed because of the lack of assistive technology devices and necessary support services.

I believe that the time has come, and indeed is long overdue, for fulfilling the promise of assistive technology for enhancing the lives of people with disabilities.

If we can develop systems for developing and making pacemakers widely available to persons in need, surely we can do the same with respect to assistive technology.

It gives me great pleasure to introduce our lead-off witness, my good friend and colleague, an individual I came to the Senate with, Senator John Kerry from Massachusetts.

Last summer Senator Kerry introduced the Technology To Educate Children With Handicaps Act. This bill focuses on improving educational opportunities for severely handicapped children through the use of assistive device resource centers.

We both agree on the important role that assistive technology can play in the lives of people with disabilities, and we agree that the Federal Government has an important role to play in helping States to expand their capacity to deliver assistive technology.

We will insert an opening statement by Senator Stafford into the record at this point.

OPENING STATEMENT OF SENATOR ROBERT T. STAFFORD

Senator **Stafford**. Mr. Chairman, I congratulate you on holding these important hearing relating to the provision of assistance technology services and devices for disabled individuals.

Advances in technological devices over the past ten years have assisted many disabled children, youth and adults to achieve greater independence in all facets of their lives. A voice synthesizer that enables an individual with severe cerebral palsy to communicate, a computer operated by a slight turn of the head allows a quadriplegic to continue to be employed, or an audio device attached to a television describing the non-verbalized action (such as a car chase scene) to a blind individual are all examples of devices that have been designed or adapted for use by persons with disabilities.

Unfortunately, the dissemination of available "new technologies" is not readily available to the disabled individual or their families and in many cases the cost is prohibitive. The research and development of new devices is an ongoing process which necessitates the availability of it to all individuals.

These hearings will focus on the need for a coordinated federal effort to assist States in the provision of these services and I look forward to your recommendations. I also want to acknowledge the efforts by Senator Harkin and the organizations and individuals which will participate in these hearings and the demonstration.

Senator HARKIN. I recognize my esteemed colleague from Utah, Senator Hatch.

OPENING STATEMENT OF SENATOR HATCH

Senator HATCH. I want to welcome you, Senator Kerry, to the committee, and I look forward to hearing your testimony and that of the other witnesses today. And we welcome you all to the committee.

This is an important hearing. It is one in which I take a great interest. I cannot be here for the full time, but I certainly am interested, and will read the record, and look over what needs to be done in this area.

I am also, Mr. Chairman, extremely pleased that one of the witnesses today is Dr. Marvin G. Fifield. He is currently the director of the Utah State University affiliated developmental center for handicapped persons. For the past 22 years, Dr. Fifield has worked as a professional providing services and developing programs for people with mental illness, mental retardation, and other handicapping conditions.

In 1986 he served as a staff member on the Senate Committee on Labor and Human Resources, and his expertise, and, of course, his advice, were very helpful to all of us here, since we were in the process of reauthorizing the Education of the Handicapped Act, the Rehabilitation Act, and the Developmental Disabilities Act as well.

So these were all very important things, and Dr. Fifield played a major role in the reauthorization of those acts.

He is also a professor in special education and psychology at the Utah State University, a member of the Utah State Developmental Disabilities Planning Council, and chairman of my own advisory council on issues concerning individuals with handicaps.

So, Marv, it is great to see you here again today, and I know everybody on this committee remembers the great service that you gave, and I hope you know how proud I am of the job you are doing in Utah, and, of course, at the national level as well.

Let me just say that this is, as I said earlier, an important hearing. We can learn an awful lot from the witnesses who will appear in this and subsequent hearings.

And I want to compliment you, Mr. Chairman, and others on this committee, for the work that you are doing in this area. And, of course, I think this is an area where we can work in a very strong, bipartisan way to do what is right for all of these individuals, and everybody throughout our country, and bring an awareness to people of how important these issues really are.

So I want to thank you for that, and thank you for allowing me to make this statement.

[The prepared statement of Senator Hatch follows:]

PREPARED STATEMENT OF SENATOR ORRIN G. HATCH

I am pleased to be at this hearing today to examine the promise of assistive technology. In today's society, technology touches nearly every dimension of the life of a person with disabilities. Modern technology has sometimes caused impairments but it has also provided a mechanism for reducing or eliminating handicapping conditions. The effective use of technology offers a most promising avenue in overcoming many physical and mental handicaps.

A survey conducted by the Department of Education reported that the United States Government spends about $66 million a year on technological research and development relating to disabilities. It also spends about $36 billion a year for income support for individuals with disabilities and appropriates over $2 billion on rehabilitation and education of the handicapped. In spite of such expenditures, it is still rather apparent that gaps in services remain and that needs are not being met.

Several years ago, I recognized that there was a problem and asked the Office of Technology Assessment to conduct a study of "technology and handicapped people." The O.T.A. study concentrated on specific concerns facing persons with disabilities by examining the developments and the use of technology as a life-cycle process. The report pointed out that we are not adequately utilizing available technology nor sufficiently encouraging future research and development. In addition, it emphasized that an insufficient number of personnel are being trained.

Over the next two days, we will again be examining the promise of technology and problems associated with its dissemination and training. Hearings such as this one provide an excellent forum to address the policy issues, to more clearly define solutions, and to provide imput at the national level. It is through the efforts of the dedicated experts here today and thousands of others throughout the Nation that we can improve the quality of life for our 36 million citizens with disabilities. Achieving this objective will not only benefit these individuals but will be of tremendous value to society in general.

Senator **Harkin**. Thank you very much, Senator Hatch.

I also want to compliment you publicly for your deep concern in this area of the handicapped, and with helping people with disabilities to lead a more fulfilling life.

Again, it is one area where, as you said, we can get good strong bipartisan support.

Senator **Hatch**. Thank you very much.

Senator **Harkin**. Senator Kerry, it is a pleasure to have you with us today. I am honored that you are here. Your statement will be made a part of the record in its entirety; and please proceed as you desire.

STATEMENT OF HON. JOHN KERRY, A U.S. SENATOR FROM THE STATE OF MASSACHUSETTS

Senator **Kerry**. Thank you very much, Mr. Chairman. I will submit my full testimony, and I will just try to summarize here if I can, because there are a group of very important witnesses, some of who are far more expert than I with respect to this matter.

Mr. Chairman, I would first of all like to thank you, number one, for holding this hearing; and, number two, for your commitment to develop an approach for all citizens with disabilities in terms of assistive devices.

The fact that this hearing is taking place, and the scope of this hearing, will lend a great deal to the effort to awaken people to the progress that we can make, and to the immediate opportunities that are there if we will only move to make them available to people. I want to thank you for your commitment and dedication to doing that.

I would also like to thank Senator Stafford, who is not here at the moment—but when I served on this committee I learned of his long dedication to these issues, literally decades of service. And my own understanding of Public Law 94-142 was greatly enhanced by my work with him. I miss being on this committee in terms of the ability it gave me to directly affect some of those issues.

Mr. Chairman, I would like to just tell you briefly about the stories of two individuals, and then say why I think this assistive device resource center bill for The Education of Children with Handicaps—TECH Act, as it is called—is important, in fact, vital.

Rick Hoyt is, in his early twenties. He has a severe case of cerebral palsy. Many people in the country have come to know Rick Hoyt because he and his father participate in marathons around the country. Almost every year they are in the Boston marathon, and have been in a number of others too.

Rick rides in a lightweight, high-technology wheelchair, which his father pushes the 26 miles and some yards distance. Rick cannot speak, cannot communicate, cannot control his body movements, but Rick is participating.

Last year I had the opportunity to join Rick in Boston where we were able to introduce a new means for Rick to be able to communicate.

He has a computer scanner board that sits on his specially constructed wheelchair. And the scanner board scans through predetermined computer messages.

And as he watches the light scan across this board, Rick has the ability to move his head and touch an electrode that is attached to the chair. With his forehead he stops the light at the appropriate message which he can read, and has total cognitive ability to understand.

At the moment that it stops, the computer then takes his message through a voice synthesizer, and Rick talks to you.

I cannot tell you the emotion that filled the room when Rick said: "Good morning, Senator Kerry, I want to welcome you here, and I am glad to have a chance to tell you about how I feel."

When he said his name, an extraordinary smile, showing a sense of being alive crossed his face and his whole being. He was communicating, he was able to participate. And we really shared, I think, a very special kind of moment, which gave me a greater understanding of the meaning of many moments that he misses, or has missed. In addition it showed me that so many other children could participate in events but miss them because nobody has taken the time to make available this kind of necessary assistive device.

Rick is currently, as a consequence of this device, attending Boston University, where he is busy getting a rehabilitative degree. He serves as an example to many, many others.

Cindy—and that is not Cindy's real name—but Cindy was a two-year-old toddler from New Jersey. Cindy, by accident of birth, was born without any arms and without any legs.

For the first two years of her life, her parents sensed nothing but desperation, a feeling that there was no chance that their daughter would be able to participate in life, or that they, as parents, had an outlet or way of providing something that gave them any hope.

They contacted a local, United Cerebral Palsy affiliate. The affiliate sent its mobile unit to Cindys home, and within 16 hours they were able to develop a walker for her; a powered walker, which permitted her, by leaning her body forward, to move forward; backwards, to move backwards; sideways, to move sideways. They are currently designing a new system which will have a whole environmental control system in it so that she can turn on the television, turn on the lights, and so forth, and participate.

Now, suddenly, her parents have a sense that Cindy does have a future, and that their ability to be able to cope with the problems that they see down the road is greatly enhanced as a result.

This particular walker cost less than $200. So, Mr. Chairman, what I would like to see happen, and what many Members of the Committee who have joined me in cosponsoring this bill, and some thirty organizations nationally who are now supporting it would like to see, is an immediate and special effort to try to deal with the problems of many other children who haven't yet had an assistive device made available to them. Many parents do not even know of the possibility of this kind of technology being applied to their problems.

What our bill would do is set up a nationwide system building from existing assistive model resource centers in the country using this system, we would have the ability to help identify a specific child's problems; identify the assistive device resources that might be applied, then train that child in using the device; assist the parents in securing the funding, whether it is through Medicare/Medicaid, private insurance, through a corporate donation; and match disability with assistive device.

These resource centers would have the ability to open up a whole new window of opportunity to children all over this country.

Currently, there are some 20,000 kids who read and write and speak with the assistance of devices, but there are some four million more who need this kind of opportunity who do not have it today.

And, Mr. Chairman, I am not going to go into the details of the bill—the staff knows them, and you know them. But this is, I think, the best of what government can do.

It is an opportunity to say that technology is not just going to be the instrument that benefits and enriches the lives of those who perhaps least need it, or those for whom that enrichment is already accessible. But it says that we are going to take technology, which is changing the way we work, the way we think, the way we communicate, the way we live, the length of time we live, and we are going to apply that to people with disabilities who need it, people who can participate in life just as fully as anybody else. And at a time when this country's resources are stretched, when we need more workers in the workplace, I think it is almost criminal, if not negligent, not to make every effort, from a practical point of view, to try and include everyone in the mainstream of society. In addition, we need to provide technology from a moral and appropriate ethical point of view of how this country ought to treat its fellow citizens, and how we ought to reach out as human beings in order to provide the best of all we have available to all who deserve it.

And I thank you, Mr. Chairman, very much for the opportunity to share these thoughts with you, and to make this bill part of this larger process which you are engaged in.

[The prepared statement of Senator Kerry follows:]

Statement by Senator John Kerry before the Subcommittee on the Handicapped, on Technology for Handicapped Individuals

May 19, 1983

Mr. Chairman, I want to commend you for holding today's hearing on technology and assistive devices for citizen's with disabilities. Also let me applaud your great work as the Chairman of the this fine subcommittee. And thank you for inviting me to return to testify before a committee that I certainly miss a great deal. I want to also thank the other members of the subcommittee and Chairman of the full Committee Senator Kennedy, for their support of the technology legislation that Sen. Weicker and I introduced last year.

Over the past two decades, technology has modernized the way society functions. It has changed the way our children learn at school, redesigned the structure of the work place, transformed our mode of travel, improved communication and entertainment systems and increased the length of our lives. And at the same time all these changes are taking place, scientists and engineers are not sitting idle; the race continues to develop new and better technologies to serve man. The technology revolution is upon us. So while we are redesigning the way we work and learn, it is imperative that society take this opportunity by tapping into these resources and adapting these changes to individuals with disabilities. Mr. Chairman the legislation that Senator Weicker and I introduced last year is designed to do just that.

In the beginning of 1987, I set out to establish a legislative initiative which would enable disabled infants, toddlers and children to access necessary technology and adaptive devices at a formative age, inorder that later on they would be insured greater independence in learing, in social settings and in general day to day life activities. Working with rehabilitation engineers, educators, therapists, state officials and a multitude of other experts in the field, I developed S. 1535, the Technology to Educate Children With Handicaps Act, known to many as the TECH Act. To date the bill has been endorsed by over 30 national organizations who represent citizen's with special needs. It has been cosponsored by a majority of the full Labor and Human Resources Committee, and a companion bill has been introduced by Congressman Major Owens on the House side. Mr. Chairman the beauty of the TECH Act and the reason I believe it has gained so much support is that it is a very basic and simple piece of legislation. It straightforwardly addresses the problems families and individuals currently face when trying to gain access to technology.

The Act will establish assistive device and technology resource systems nationwide. These systems will provide the full range of necessary services to handicapped children and their families, so that through the use of technology and assistive devices kids can gain more independence in the class room and in their social setting. It will offer families and children a sense of hope in their future by ensuring that these kids have a much fuller one than we may now imagine.

The centers will assess the needs of, and train specialists to assess the needs of handicapped children, in order to determine what type of assistive device is most appropriate for a child in order to to help him or her get the most out of school.

Once it is decided what kind of assistive is best, the center will help find the all important funding for the technology or device. Whether it is working with a computer company to have one donated, contacting a private insurer to work out a payment scheme, getting funds from medicaid or through EHA grants, the resource centers will help parents through the mind boggling myriad of funding possibilities to get the necessary device.

The system will train parents and educators and children in how to use assistive devices so that they feel comfortable with the device. The center will then provide follow-up services with the schools and families to make sure that all is going well. Then when a child outgrows their device, and is ready to move on to more advanced equipment, they will be their to help find and design new equipment and act as part of information and equipment clearinghouse for the old [illegible] device.

Finally the resource centers will disseminate information throughout the states on assistive devices and their availability. In general terms the assistive device resource systems will take a child and their family from A to Z in regard to the necessary delivery of services.

I would like to share with the Committee for a moment the stories of two different individuals who because of assistive device technology are now able to effectively interact with the world around them. Many of you may remember Rick Hoyt from my home state of Massachusetts. Rick has severe Cerebral Palsy which prevents him from being able to speak or control his body movements. Last year, I met with Rick and through his augmentative communication device, he explained to me how unbearable it was growing up in complete isolation, unable to communicate with his family, friends or actively participate in school. In addition to being removed from the mainstream of society Rick expressed his frustration with not being able to participate in any recreational activities. Today with the use of his specially designed lightweight wheelchair, Rick regularly participates in the Boston Marathon. In addition, because of his communication device he is currently attending Boston University and receiving a degree in Rehabilitation Counselling.

Another individual, I would like to mention is Cindy, a 2 year old toddler from New Jersey who because of a birth defect, was born without any arms or legs. Cindy could not do the normal things that toddlers do to learn about the world around them. She could only roll around and that resulted in intense rug burns on her body. Her parent's desperate, contacted the state's UCP affiliate who visited Cindy in their mobile technology van. Within 16 hours they developed a powered walker that has enabled Cindy to be independently mobile through out her house. When sitting in her walker, by pressing her chest against a tray she can move forward, leaning to the side she can move right or left. This device was constructed at a cost Mr. Chairman of less than $200. Today Cindy is learning about the life around her. Currently the engineers from the technology van are developing a powered wheelchair that will have a built-in environmental control system to enable Cindy to turn on light switches and the television. The critical thing that we must note here, is that today Cindy's parents and Cindy herself have a vision for her future. Once in a state of desperation, her parents now can imagine her holding a job and participating in society. In a couple of years, when Cindy reaches school age, she is expected to go to a regular school and her family anticipates a bright and successful life.

The point I am making here is that technology offers severely disabled citizens like Rick and Cindy a chance to focus on their abilities. It was not too long ago that the term severely disabled meant a life of total dependence and the inability to be educated or employed. Already, today it is estimated that over 20,000 Americans now read, write and speak through the use of specially adapted personal computers.

Think about what tomorrow will bring for the more than 4 million handicapped students if the TECH Act is enacted. Furthermore, computerized keyboards, now are fashioned with switches operated by a persons hand, foot or head, enabling communication systems to be available to nonverbal individuals with limited mobility. Other devices include laser canes for persons who are vision impaired, electronic ears for the hearing impaired to name a few.

Our Nation has clearly entered the high technology age. We have reached an era dominated by sophisticated computer technology. At a time when every classroom and many households and workplaces have computers, it seems particularly appropriate for handicapped children to benefit most from such available technology. Let's take the existing assistive device resource center models and give them a boost by applying their systems nationally.

The TECH Act will do this by ensuring an increasing role of technology in the school system, thus enabling disabled children to compensate for their limitations. It is clear to me that education holds the promise for handicapped children to be able to gain employment down the road. The ability of a child to develop their cognitive, social skills from the beginning is critical to developing and setting the stage for a decent education and a necessary independence in their environmental setting. By targetting our young people the TECH Act is investing in this nations future. People with disabilities can fullfill jobs if they and society have the right attitude. In fact, many states today boast about a very low unemployment rate. As that trend continues, employers are finding it extremely difficult to attract and retain qualified workers. Through assistive device technology and appropriate education I believe we can develop a new generation of workers.

Mr. Chairman in closing let me say that I feel the TECH Act provides a seed for assistive device technology initiatives.

I understand that the Committee is working to develop a comprehensive approach towards technology for all disabled Americans. I could not agree more that it is indeed needed and I am committed to doing all that I can to work with you towards achieving such a commendable goal.

I do feel however, that the TECH Act is a starting point towards that objective. Over the past year the legislation has been scrutinized by many and gained wide support. Mr. Chairman with your help, I believe it will be enacted this year. As additional legislation is developed it will augment what the TECH Act sets out to accomplish and that is to provide youngsters with the independence in the class room and home which will enable them to become active, employable, participating adults. It is my hope that the Committee will move the TECH Act forward so that we can achieve passage before the end of this session. Thank you.

Senator **Harkin**. Senator Kerry, thank you very much for not only your fine testimony, but your foresight, and your involvement in this area.

I would just note for the record that you did introduce this bill last June 23. So obviously your interest in this does predate this hearing.

I want to just get the concept clear in my own head of what you are seeking. There are resource centers in each State. States would set them up. There would be a Federal share. And the centers would be focused on early intervention; providing assistive technologies to the young.

Senator **Kerry**. It would help with early intervention. But it would really take them from A to Z through the process of the use of an assistive device. Even make a device available to them. But more importantly, once that initial assistive device has been fully utilized by a child, and the time has come to graduate to a new device, or perhaps even to none whatsoever, at that point there is obviously a transition point.

That would be the point that we would envision the technology resource centers phasing out for a child. They would assist in pointing the direction for that individual into the next level or the next tier, or the time of independence.

Senator **Harkin**. Do you envision a center that, for example would serve people as they progress from early childhood to adulthood and have needs for different devices as you just said?

Senator **Kerry**. Correct.

Senator **Harkin**. Are you envisioning a center that would in some way loan out a device to a young person, and then when they graduate to the next device it would come back in to be passed on to someone else?

Senator **Kerry**. I am not sure that all of these devices, Senator, lend themselves to that. But certainly some do. I think there is a considerable amount of flexibility in the concept of the centers, dependent on the needs of a particular State, depending on the resources that are available in each State.

As you know, there is a formula that has been set up. I think the total cost is envisioned at around $20 million. The formula that is established would break that up between States so there is a fixed amount of money according to the formula.

States would have to be creative in their application of the funds. Some States have more existing children's services, services for people with disabilities, and you would want to tap into those.

So I do not think there is a rigidity to the form it would take in each State. There would be great flexibility under the departments within the States who would manage the system to make it work according to the needs of that State.

I don't think this envisions us in a micromanagement status.

Senator **Harkin**. I see. I was just wondering about utilization, because obviously these devices could be utilized many times.

Senator **Kerry**. Some of them can.

Senator **Harkin**. Yes, some can.

Senator **Kerry**. And in those cases, they should be reused and made available to others if there are not enough devices to go around.

Some of the equipment will be highly specialized. What happens is, if you have a particular individual who comes in with a problem, you have experts, you have rehabilitative engineers, you have therapists, you have State health personnel and others participating, and you may design a particular system with the help, let us say, of a Wang computer, or a Digital or a Tech or some particular company that has an expertise.

And you may wind up with a piece of hardware that is so specialized that it assists that individual but does not have another use, except perhaps in another part of the State.

But what would happen with these centers is that because they exist, and you have one in every State, you would immediately have the creation of a network and a data bank, and that data bank would be able to assess the needs State by State, and you would build on that so that you could have an interstate loaning process, you could have one State building on the experience of another device, and so forth.

And I think it simply provides exactly what it is called—a resource center. In some cases, they are going to be breaking new ground. In other cases, they are going to be making some very well known device to parents who simply did not know where to go and how to get them.

Senator **Harkin**. You know—and I am going to be asking this of other witnesses, is there a central place today where you can go now, a clearinghouse?

Senator **Kerry**. Not really. In Massachusetts the model center has tried to act as that. But to the best of my knowledge there is no one place now. There is no place that acts as that kind of clearinghouse, which is part of this concept.

People will contact UCP, people will contact services for the handicapped; they will contact the State division.

Senator **Harkin**. Thank you very much, Senator Kerry.

Senator Metzenbaum.

OPENING STATEMENT OF SENATOR METZENBAUM

Senator **Metzenbaum**. Thank you. First of all, I want to commend both Senator Kerry and the Chairman for moving forward in this area, because I think the thrust of each piece of legislation—I am a cosponsor of yours, Senator Kerry, and I do not think the Chairman has asked me to cosponsor his, but I think you both move in the right direction—and I would hope that at some point the two authors of the bill would sit down together and work out a package, because I think the committee would be supportive.

My question is about the centers—I hear dollar signs up there. And I am concerned as to whether or not, in staffing and setting up these centers, we get enough bang for the buck, or whether we will be siphoning off some of the dollars that could be used for the handicapped in order to provide personnel to staff the centers and just the overall cost of running the centers.

I wonder if you would address yourself to that, Senator Kerry?

Senator **Kerry**. Well, first of all, Senator, let me address myself to the first comment. We are very anxious to work with the Chairman and others in putting a package together.

I think the attractiveness of this particular piece, which we started work on in early 1987, was that it is simple, it's pretty straightforward, it's not trying to bite off too much of the apple at one time.

And I think the simplicity was appealing. But obviously we are anxious to join cooperatively in whatever effort best meets the need. There is no proprietary authorship process here at all.

As to the second part of it, it is our sense that both on a cost-effectiveness basis—and again we are modelling this, we have several centers in Massachusetts that have been attempting to do this. And it has proven cost-effective, but at the same time it does take some dollars to effect.

We are not talking about setting up a separate agency that would duplicate existing services. We are really talking about a clearinghouse that is nonexistent today, which can bring together other resources.

Now, you are going to have to have some staffing in that. As I say, the current cost estimates nationwide are a total of $20 million.

Senator **Metzenbaum**. That would be one center in each State?

Senator **Kerry**. That is one center in each State—could be several if they want to divide it up appropriately. They have that option. We are trying to leave as much flexibility to the States.

Some States, obviously—and I can envision in your State or California or New York or places where they may feel there is greater need to reach out with a mobile van system or some other parts of it.

But clearly not every State would have the same needs.

Senator **Metzenbaum**. Would the center go out and buy, or how would it obtain various——

Senator **Kerry**. No, the center would not buy. The center acts as a processor—the center acts as a catalyst, if you will, between the potential technology producer and user.

The funding would come through any one of a number of sources. In many cases we have been able to get through our centers to get corporations to donate their technology. They have gladly used this as a means of trying to test new technology—of trying to find out whether or not there is a larger market, and so forth.

And in many cases, they have done it because they think it is the right thing to do,and it is appropriate.

There is private insurance that is available, but in many cases people do not know whether Medicaid or Medicare might cover it. It does in many instances.

And this would help bring them together and act as the troubleshooter, if you will, for the parents and the user in order to help them break the red tape and get these things done.

And again and again the models have proven that they have been able to do that.

Senator **Metzenbaum**. Does the legislation contemplate any sharing of costs?

Senator **Kerry**. Yes, it does.

Senator **Metzenbaum**. Thank you very much, Mr. Chairman.

Senator **Harkin**. Again, I just want to ask John this is a resource center that would basically operate statewide; that would provide both information and services; and that could provide devices and act as a clearinghouse on the State level.

Now, would you envision, perhaps regional centers that would back these centers up, or Federal centers to back these centers up, or anything like that?

Senator **Kerry**. That is not what we really envision here at this time, Tom. I think, again, there is room for some creativity and some flexibility, obviously, according to the needs here.

What we have envisioned, today, first of all, many people do not know where to turn. And they turn to somebody, and that person is not aware of funding mechanisms, but they may say, well, I have heard of this device, or something.

What you would have is a center staffed by people whose job it is exclusively to know what resources exist, what is being worked on, what sources of funding are available, what companies might be able to assist and create, and then put those people together and essentially keep the process moving, make certain that they have not just been shunted off and the process forgotten; make the telephone calls that assist in making sure that people are completing the tasks that they said they would; and in many cases, leveraging if you will for things to happen where they would not.

And that is precisely what we have seen is able to happen. You have a couple of experts who, when the people come in, and they say, we have this problem, we do not know what to do, they can say to them, well, we know what to do. There are five different places that have dealt with this problem before. I am going to put you in touch with the people.

They earn a certain respect among that network so that people begin to respond to them automatically knowing that they have got credibility, knowing that there is some clout. And it just leverages and raises consciousness as well as solutions to a problem that has been kind of under the table, hidden, shunted aside, ignored, whatever; neglected.

It is not envisioned as the place where there will be a lot of hardware on the shelf, or people are suddenly going to become contractors of services in a specific way or anything. It is strictly a leveraging clearinghouse information-collecting data bank processing middle person effort to provide assistance where none has existed.

Senator **Harkin**. Okay, I just wanted to get a better idea of the concept.

It could be integrated with a broader scope of assistive technology to all age groups?

Senator **Kerry**. Oh, sure, no question about it. It could. I think the thing you have to be careful about there, obviously, and this is why we pin pointed this beginning area. We chose education age because mostly in terms of need it was our sense that when you have people at that formative stage, it is so critical to guarantee that the formative process is responded to in a way that maximizes later ability to participate.

And it seemed to us that that is where the most critical need was, both in terms of the child and parent as well as family process.

But I think you have to be careful of cost if you start getting overly comprehensive in one bite.

Senator **Harkin**. Thank you very much.

Senator **Kerry**. Thank you, Mr. Chairman.

Senator **Harkin**. Our next witness is a very famous individual, Teddy Pendergrass, a well known singer, songwriter, and record producer.

As many of you know, Teddy Pendergrass was paralyzed after an automobile accident in 1982. Since that time, with the help of assistive technology, Teddy Pendergrass has made an inspiring comeback, just like his new album, "Joy," that has just come out.

Mr. **Pendergrass**. Thank you very much, Senator.

Senator **Harkin**. Mr. Pendergrass, I am just as pleased as can be and honored to welcome you here today. I look forward to hearing your testimony. I understand you are with Mr. John Hartmann.

So again, welcome to the subcommittee. We are honored to have you here, and look forward to hearing your testimony. Please proceed as you so desire.

Senator **Metzenbaum**. Mr. Chairman, it was my understanding that Mr. Pendergrass was going to sing his testimony. [Laughter.]

Senator **Harkin**. Did you have an opening statement?

Senator **Metzenbaum**. No, I will waive my opening statement, but I understand Mr. Pendergrass was going to sing his testimony.

Mr. **Hartmann**. We get paid for concerts, Senator. [Laughter.]

Senator **Metzenbaum**. There is more than money that can be rewarding.

Mr. **Hartmann**. That is why we are here today, sir.

Senator **Metzenbaum**. Spoken like a true agent.

Senator **Harkin**. Thanks again; please proceed.

STATEMENT OF TEDDY PENDERGRASS, ACCOMPANIED BY JOHN HARTMANN

Mr. **Pendergrass**. Thank you, one and all, for certainly inviting me down. This is a great opportunity for me just to be able to speak on something as near and dear to myself and all of us.

Again I say, thank you very much. And I would just like to start just by kind of rehashing those wonderful words that you so nicely gave me in those credits in your introduction.

But certainly now it has been over 20 years now that I have been dedicating my life to the music industry. And that was my life, my love, and everything that I worked for.

Six years ago, as you mentioned, I was in a car accident. At that time it left me not knowing exactly what I was going to do with the rest of my life.

Before the accident, I was expanding my horizons, expanding my talents. As you mentioned, in production and arranging, and all facets of the music industry.

When I had my accident, I was asked, well, what are you going to do with your life? I very quickly responded, I am going to continue to make music.

At that time, I did not really realize how I was going to do it, but then, along came this wonderful thing that they call MIDI. Suddenly there was something that was brought into my life that was something of an advance in technology that I had never heard of before.

MIDI, in case you do not realize what that is, it is Musical Instrument Digital Interface. I guess you say, well, what is that?

What MIDI allows us to do, it gives us the option of recording, composing, arranging, literally doing anything with a piece of music, by manipulating computers.

As in every piece of music, or a majority of music that you hear today and that we listen to, the majority of it is computerized. Now, instead of musicians playing the music, musicians now play computers.

So that meant to be a chance for me to continue in an industry that I live for. At that time, or during that time, which was about oh two years ago, I would say, I was discussing this same situation with a very close friend of mine who was also a handicapped musician.

He told me of a gentleman that was designing a system for him that would allow him to continue in the music industry. Right away I asked, well, who is this gentleman?

And I found out this gentleman's name is Dennis Turner. So I asked if I could contact Dennis Turner, and in return, Mr. Turner contacted me.

Now, Mr. Turner is a rehab engineer. And what we did collectively was to sit down and discuss our possible goals, what we wanted to achieve, how far did we want to go, and what did we want to do.

And as I said, collectively, we came up with a system that would allow us to continue in this industry at a level that any other musician can compete in this industry.

Upon us gathering information that we needed, together we contacted the Pennsylvania office of vocational rehab. With their willingness to look into the future, they, too, were in agreement that this was the way to go.

They, along with Mr. Turner and myself, we started securing different computers, and we started securing different keyboards and pianos and synthesizers. Along with Mr. Turner, I have been being trained, trained so that I can compete at any level with any other musician, and it becomes my mind against his mind.

And where it also becomes irrelevant, totally irrelevant, about my handicap. And I can compete in an industry that is very competitive, where I do not have to play an instrument. More or less I can play with computers.

Now all I wanted to mention is that this technology exists at every level for everything. We have a technology. And it is not that we created something that was not already existing. All we did was take existing technology and adapted it to my needs.

Along with that, that is the point I wanted to bring out, since the technology exists, all we need to do is adapt the need for everyone, and for all people, and we can make those people individuals that can continue in any industry at all levels.

And what we need to do is to acquire this equipment, at all levels, whether it be corporate or whether it be creative, or whether it be anything that you choose to do; we can accomplish this.

Then we need to acquire the training, as I am being trained by Mr. Turner. We have to acquire the training for these different computers, and different things that can keep us working people.

Once we can acquire the training, then we need to be able to get a job, to work these different situations. And that will keep us independent and self-sufficient.

But once we get a job, we need to get to this job. So that was where technology is important at all levels, getting to the job, getting the job, being trained for the job. And certainly, it will help us to hold a job.

Because certainly there are a lot of surprises that come along with working, and a lot of adjustments that have to be made. And as technology advances, we need to be constantly, as everyone else, constantly trained and retrained so that we can compete in industry at the same level with anyone else.

And that will allow us to grow with the job, and allow us always to be self-sufficient people.

Now, I have come to realize that music and technology suddenly got married, suddenly got married. And what that shows me is that now they are one and they are together, and that allows me to compete at the highest level and be as competitive as anyone else in this industry.

And therefore, that erases the handicap, which means that it doesn't exist in my industry any longer.

And I would just like to say thank you for giving me a minute just to speak my piece.

Senator **HARKIN**. Thank you very much for your very fine testimony. I was reading through your written statement as you were talking, and a couple of things really stood out for me in your testimony.

And that was that you basically said you had input all along the line. I assume that Dennis Turner may not have known exactly all of what you wanted to do, but you knew what you wanted to do.

Mr. **PENDERGRASS**. Exactly.

Senator **HARKIN**. So you had input all along the line——

Mr. **PENDERGRASS**. Exactly.

Senator **HARKIN**. To get this MIDI so that you could use it. And I think that is a very important point.

And I do not want it to be passed over. You are the first person who has made that point today about your input all along the line.

Mr. **PENDERGRASS**. That is true. I think it is very, very important that the handicap have the majority of the say-so in the technology that is adapted for their use. Because who better to know what is needed than the handicapped themselves.

And I think working alongside of the people that can make this technology work is just making one and one to equal two.

Senator **HARKIN**. Well, technology changes, right? As technology changes, you are going to have to keep up on that, so there is going to have to be continual training and adaptation?

Mr. **PENDERGRASS**. Constantly, as in any other industry, as for anyone else. As technology changes, one must always be trained to keep up with technology.

Man makes the technology, but also, man uses the technology, so man must know exactly how to use the technology efficiently.

So it makes no difference whether we are handicapped or nonhandicapped, we still need to be trained on the technology.

Senator **Harkin**. I think that is a very important concept, extremely important. We have got to remember that even non-handicapped individuals, involved in whatever business, have got to adapt, right? You have got to be constantly training yourself.

Mr. **Pendergrass**. Always, always.

Senator **Harkin**. So I think maybe one concept that we have got to get clear is that making an assistive technology device available, does not end it. There have got to be continual upgrading and changes as we go along.

Mr. **Pendergrass**. And I am finding out, if I may add as well, that the technology that is becoming available to me, I am finding out ways that I can increase or further the technology in the industry that I am in, and it is not yet available.

So at this point I am creating new technology.

Senator **Harkin**. That is interesting.

Mr. **Pendergrass**. That puts my mind just about where the people are that is creating the technology.

Senator **Harkin**. Exactly.

Mr. **Pendergrass**. It is mind to mind, not legs, but minds.

Senator **Harkin**. Before your accident, were you much of a technology nut?

Mr. **Pendergrass**. Not very much at all.

Senator **Harkin**. But you are creative? You have a creative mind?

Mr. **Pendergrass**. Of course, of course.

Senator **Harkin**. That is right. And so now——

Mr. **Pendergrass**. I would say, 30 million records later, yes, I am. I would say so.

Senator **Harkin**. I would say so, too. So see, that is great, because with the creative ability that you have, you can take a look toward what needs to be done next. Now that you are interested in this technology, you are able to think a couple of steps ahead of where other people are.

Mr. **Pendergrass**. That is because I am not working for the technology, the technology is working for me.

And that is where it is important for all handicapped individuals, that the technology works for them, and they do not work for the technology.

Senator **Harkin**. Good point. Thank you very much.

We welcome Senator Stafford to the subcommittee, and recognize you for an opening statement.

Senator **Stafford**. Well, thank you very much, Mr. Chairman. I want to congratulate you upon holding these hearings. I am looking forward to the rest of the testimony.

I wish I could have been here earlier, but I had to be at another committee, and I am looking forward this noon to some of the actual equipment being demonstrated.

I would ask unanimous consent, in the interests of time, that my opening statement be placed at an appropriate place in the record as if read, and I have no questions.

Senator **Harkin**. Thank you very much, Senator Stafford.

Senator Metzenbaum.

Senator **Metzenbaum**. I am a little bit curious about the technological approach. By using this piece of equipment called the MIDI, you are able to actually hear the music?

Mr. **Pendergrass**. I will tell you exactly what I am able to do. I am able to compose, I am able to arrange, I am able to rearrange, I am able to do anything—I am able to play drums, I am able to play piano, I am able literally to play every piece of instrument that would be included in a 100-piece orchestra, and about 100 other pieces.

I am able to utilize mix, rearrange, change sounds, create sounds that are different, that is not heard, use my creativity to the fullest that I am creating at the time, and be able to do about 100 percent more with this computer, with this MIDI, than one human being can do without MIDI.

Senator **Metzenbaum**. Can you give us some idea as to what the cost factor was in developing the MIDI?

Mr. **Pendergrass**. At this time the cost is fairly reasonable, I would say. As I said before, we are not recreating the wheel. The technology is already available. It is on the shelf.

All we did is just adapt it for my needs. It is not something that someone went out and said, well, let us just invent this.

So the cost is the cost that it would be to go to a musical store and just buy a DSS-1, which is a digital sound sampling machine, which allows us to create and recreate different sounds and invent different sounds, play them through a keyboard, a piano, and synthesized through a computer.

The cost is, I suppose, about, for one keyboard, $2,000. The cost of a MacIntosh computer, plus the hard disk, plus any little adaptive equipment. That is just one keyboard.

Totally to be able to write and rewrite and rearrange a total symphony, which would include approximately 100 to 150 instruments, the cost would be no more than $10,000.

Senator **Metzenbaum**. And is there audio available also? In other words, as you compose, are you able to play it back and hear it?

Mr. **Pendergrass**. I am able to play it back at studio quality. I am able to play back perfect sound. I can then take my software, take it from my computer, take it to the studio, make any additions, put it to tape, save time and put it to record in less time and have a finished product in about a third of the time that it would take if I did it in the studio.

Senator **Metzenbaum**. Thank you very much. That is fascinating.

Mr. **Pendergrass**. I think so.

Senator **Metzenbaum**. May I ask one more question? Dennis Turner is from Yellow Springs, in my State of Ohio; I am proud of that fact. I recollect meeting a man over in that part of the State who by electronic impulses was able to provide actual activities and leg movement and arm movements for people who could not otherwise do that.

This is not the same man to the best of your knowledge, is it?

Mr. **Pendergrass**. I have no knowledge whether this is the same gentleman.

Senator **Metzenbaum**. I thank you.

Senator HARKIN. Teddy Pendergrass, thank you very much, for not only being here, but you are a great inspiration to all Americans, just for your courage, your determination, your creativity.

I think you represent the best in all Americans. Thank you for being here.

Mr. PENDERGRASS. Thank you. [Applause.]

Senator METZENBAUM. Mr. Pendergrass, what just happened is quite unusual. Usually the chairman says to the audience that applause and comments are not called for. To have the chairman start the applause is quite a compliment to you.

Mr. PENDERGRASS. Thank you Senator Harkin.

Senator HARKIN. Thank you very much.

[The prepared statement of Mr. Pendergrass follows:]

STATEMENT OF

TEDDY PENDERGRASS

to

THE SENATE SUBCOMMITTEE ON THE HANDICAPPED

with respect to

ASSISTIVE TECHNOLOGY FOR PEOPLE WITH DISABILITIES

MAY 19-20, 1988

Hello - my name is Teddy Pendergrass. I have spent the last 20 years of my life involved in the music business as a singing artist, writer, producer and percussionist.

Six years ago I was in an automobile accident which caused a spinal cord injury and changed my life. I had to make a decision whether to call it quits or go on with my life. While in rehabilitation, a therapist asked me, "What are you going to do now?" I answered, "I am going to make music."

Before my accident, I was actively working on developing my skill and talent in writing, arranging, performing, conducting and engineering. Since my accident I have been producing and recording my own albums, as well as producing other artists, but, I have not been able to be involved in the hands-on process of making music - - until now.

Over the last four years, I have watched a revolution in the music industry take place, based upon recent advancement in electronic music technology, generally called MIDI (Musical Instrument Digital Interface). This MIDI revolution has changed the way popular music is written and recorded. Most of the music you'll hear these days is created by electronic instruments, computers, and music software.

About a year ago I was contacted by Dennis Turner, a rehabilitation engineer in Yellow Springs, Ohio, who offered to develop an accessible MIDI system for me, which would allow me to fully and actively participate in this musical revolution. Dennis and I contacted the Pennsylvania Office of Vocational Rehabilitation, who also recognized how such a system could enhance my effectiveness, both as a musician and a producer. The Pennsylvania OVR decided to support this project by hiring Dennis as a consultant and assisting in the development of an entry level system. The word "development" is important because we worked together as a team to choose the equipment, the software, and the overall approach.

Throughout this process, I have felt that my input was important. I had the power to veto ideas, and I sometimes did. My ideas are included in the training approach, the short-term and long-term goals, and every other aspect of this project. Dennis and I are currently designing a work station which will make the best advantage of available space in my home studio; serve as an office workspace; allow me to independently access several telephone lines; write music, and be "custom fit" to my wheelchair height and range of motion.

This technology gives me the flexibility of continuing my work on a higher technical scale. It lets me do more than I could have done before my accident. In the past, I would have needed someone to jot down my ideas for me because I am not a pianist, but with my system, now I can do all that myself; I don't need to wait on anybody. The MIDI system, which I am now learning to use, will enable me to create, arrange, orchestrate, and conduct my own musical ideas in virtually any style. I will also be able to work directly as a co-writer/co-arranger with other artists, with almost limitless control over each piece of music.

One of the most exciting aspects of my system, is that it is not based solely on adaptive technology. Dennis Turner designed a very simple modification which allows me to use this standard technology in exactly the same way as thousands of other musicians. Because I am able to use standard, off-the-shelf technology, it now boils down to my mind and my computer competing with any other musician's mind and computer.

I think this brings up a very important point. Because of a very simple modification developed by a rehabilitation engineer, I am able to compete on an equal basis with any musician who makes his living in the music business. When it comes to my music, my disability is not important.

But finding and acquiring appropriate technology (which can be difficult) is only part of the solution. Even the best technology can end up being useless without proper training for the user. Providing effective, affordable, and accessible training is a vital piece of the puzzle. Training should also be provided to rehabilitation professionals to help them deal with the enormous responsibility of choosing the right technology for each individual case.

CLOSING STATEMENTS

Thank you for this opportunity to speak with you today. As Americans, we have a long history as pioneers and innovators. We are living in the midst of great technological change. These changes offer tremendous opportunities for people with disabilities. These changes also present tremendous challenges. We must try new approaches, based on common sense and ingenuity, to put the power of technology into the daily lives of persons with disability.

Senator **Harkin**. As Mr. Pendergrass leaves the room, I would introduce our third panel, Leo Lucas of Boston, Massachusetts; Al Cavalier, Director, Bioengineering Project, Association for Retarded Citizens of Arlington, Texas; Carolyn Rossick on behalf of Howard "Rocky" Stone, Self Help for the Hard of Hearing in Bethesda, Maryland; and John C. DeWitt, Evaluation Coordinator, National Technology Center, American Foundation for the Blind.

Our next panelists will present information on the efficacy of technology for persons with different types of disabilities, and the problems that those individuals might have in getting access to assistive technology.

We will hear first from Leo Lucas representing United Cerebral Palsy, who has recently returned to school with the aid of assistive technology.

Next we will hear from Dr. Al Cavalier, director of the Bioengineering Project of the Association for Retarded Citizens, and Carolyn Rossick, who will be presenting testimony on behalf of Mr. Stone, director of Self Help for the Hard of Hearing.

Finally, John DeWitt, Evaluation Coordinator of the American Foundation for the Blind's Technology Center.

Leo Lucas has cerebral palsy, and uses augmentative communication. He was never allowed in public school because of his disability, and received 500 hours of tutoring in lieu of formal education.

Now, with the aid of assistive technology, at the age of 45, he is a student at Northeastern University.

Leo, welcome to the subcommittee. We will put your entire statement in the record in its entirety, and again, in the interests of time, I would ask if you all could limit your testimony to five minutes and your statements will be put in the record.

Leo Lucas, welcome to the subcommittee; please proceed.

STATEMENTS OF LEO LUCAS, BOSTON, MA; AL CAVALIER, DIRECTOR, BIOENGINEERING PROJECT, ASSOCIATION FOR RETARDED CITIZENS, ARLINGTON, TX; CAROLYN ROSSICK ON BEHALF OF HOWARD "ROCKY" STONE, SELF HELP FOR THE HARD OF HEARING, BETHESDA, MD; AND JOHN C. DeWITT, EVALUATION COORDINATOR, NATIONAL TECHNOLOGY CENTER, AMERICAN FOUNDATION FOR THE BLIND

Mr. **Lucas**. Good morning. My name is Leo Lucas. I am here to speak to you today as a representative of the United Cerebral Palsy Association.

I am 45 years old. I am nonspeaking. Until I got my first electronic communication system. I always had to have someone with me to be my interpreter. That made me feel as if I were a prisoner in my own world.

I got my first communication aid in 1979. It was a Handivoice 120. After I got it, my life changed completely. I started to go out and meet people. I joined a group of handicapped people. I felt better about myself because I could communicate with people outside my family for the first time.

In 1980 I met a friend who went to Cape Cod Community College. I told him that I wanted to get more education, but I did not know where to start.

He introduced me to his adviser. When she told me that she wanted me to take courses there, I could not believe it. I got a B average. I could not have done that without my communication aid.

In 1987, I came to Northeastern University because I could get more help from the Department of Handicapped Services, which enabled me to take several courses at the same time, at which point I got a Touch Talker with Minspeak, which is a new communication system which does not use a number code. Instead, it raises grades of manual signals.

Later I got a DEC Talk, which is a good quality speech synthesizer, which you are listening to now. It has a choice of seven voices. I am still learning to use this system. It has a large vocabulary. It has a core vocabulary of over 1,000 words that I can use to generate sentences.

I can put up to 2,000 ready made sentences in it. I push strings of two or three symbols which accesses the vocabulary or sentences. It takes a great deal of time to memorize everything. I work every week with three terrific people in the Speech and Hearing Clinic at Northeastern University to learn my vocabulary.

At this point in my life, I can make a choice. Either I can stay at home and waste my life, or I can go out and try to make the most out of it, which means being able to communicate with strangers, and learning how to talk for myself.

It may not be perfect. But it is a good beginning. Let me tell you what I had to do to get where I am. I never would have assumed, between the years of nine and 15, I had about 500 hours of home tutoring. I gradually taught myself to read.

About one year after I got my Handivoice, I met a friend who helped me learn to read. I got my first communication aid through the Massachusetts Rehabilitation Commission. It took me a year to get it. I did a lot of pushing.

I kept calling until I finally got it. People tried to put me off, but it was important to me.

In 1985 I went back to Massachusetts Rehabilitation Commission because I read a couple of magazine articles about new computer-based communication systems. There were some which would handle not only communication, but also with school work.

I went around to a number of organizations to get advice on what sort of system I needed. To start with, I went to Rehabilitation Engineering Center, which was involved with research. I was not too pleased with what they did; they really didn't show me what I wanted. Then my counselor back in Massachusetts Rehabilitation Commission advised me to go to Children's Hospital in Boston to see what was commercially available.

They showed me the Touch Talker and DEC Talk. I could not believe my ears. There were the usual administrative delays getting everything approved and delivered in time for me to start as a student at Northeastern University in the fall of 1987.

However, I have learned a few lessons: persist and persist and persist. I am now in my first quarter of a bachelor's degree in psychology. Now that I am a regular student at Northeastern, I have to do everything other students do. That means lots of reading and writing assignments. It is all I can do to keep up.

My major problem at the moment is writing. My mother bought me an Apple IIc, but my spelling is poor, and my typing is very slow. We are investigating a word processing program developed by IBM which allows me to type only the first few letters of a word and it will predict the rest of it.

Funding for my communication aids have been from the Massachusetts Rehabilitation Commission. Altogether, both of my devices cost $5,700. That may seem like a lot of money, but if you put yourself in my position, what would you think?

My ambition is to work with other severely handicapped people prescribing communication and writing systems. That is still a few years down the road.

I am working with people at Northeastern University to establish some directions for myself, and to make sure I have the necessary skills before I graduate.

I have waited for this opportunity for many years. If there is any way I can accomplish it, I will do so. Technology for some people is a luxury. For nonspeaking people like me, it is a means to a meaningful life.

I hope that this committee will have other people like myself to benefit from the assistive technology which is now available.

The United Cerebral Palsy Association believes that Congress can aid in the following ways.

First, by ensuring that a free and appropriate education system is available and can move assistive technology services.

Second, by creating a capacity incentive to help States improve their current systems for improving technology.

Thank you for giving me the opportunity of addressing you today.

[The prepared statement of Mr. Lucas follows:]

STATEMENT

RESPECTFULLY SUBMITTED

TO THE

UNITED STATES SENATE LABOR AND HUMAN RESOURCES

SUBCOMMITTEE ON THE HANDICAPPED

ON

ASSISTIVE TECHNOLOGY SERVICES

MAY 19, 1988

PRESENTED BY
LEO LUCAS
BOSTON, MASSACHUSETTS

ON BEHALF OF
UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

Accompanied by
Karen Franklin
UCPA Governmental
Activities Office
1522 K Street, N.W.
Washington, D.C. 20005

U C P A Governmental Activities Office Washington, D.C

Good Morning! My name is Leo Lucas. I am a student at Northeastern University. I am here today to testify on behalf of United Cerebral Palsy Association, Inc. United Cerebral Palsy Association is a private, non-profit agency with 180 affiliates in 45 states concerned with meeting the needs of persons with cerebral palsy, and similar disabilities and their families. United Cerebral Palsy is very concerned with ensuring that these individuals are educated to their fullest potential, and are given the opportunity to work and live in their community. We believe that in order for this to happen these individuals must be afforded the opportunity to benefit from a wide variety of assistive technology services. Since UCP was created in the 50's, the organization has been involved in encouraging the development of assistive devices and a service system to respond to the needs of individuals with severe disabilities.

Soon after the Association was formed, the Cerebral Palsy Research and Educational Foundation was established to assist us in our goal to increase the availability of assistive technology. The Foundation has provided over $21 million dollars worth of grants to individuals, organizations and universities for assistive technology research and development. UCP affiliates across the country assist individuals gain access to assistive technology services in early intervention, educational and adult service programs. The National Office of United Cerebral Palsy Associations is also very involved with expanding assistive technology services through the efforts of the Community Services

Division. Our testimony today will outline through my own life how assistive technology can radically change the lives of persons with severe disabilities. We will also make recommendations for federal legislation that would help to eliminate many of the barriers which are currently preventing individuals with severe disabilities from meeting their full human potential.

I am non-speaking. Until I got my first electronic communication system, I always had to have someone with me to be my interpreter, usually my mother or my father. That made me feel as if I was a prisoner in my own world. I got my first communication aid in 1979. It was a Handivoice 120. After I got it, my life changed completely. I started to go out and meet people. I joined a group of handicapped people. I felt better about myself because I could communicate with people outside my family for the first time.

A year after I received a Handivoice, I talked to a friend who went to Cape Cod Community College. I told him that I wanted to get more education but I didn't know where to start. He introduced me to his advisor. When she told me that she wanted me to take courses there, I couldn't believe it. I got a B average. I couldn't have done that without my communication aid.

In 1987, I came to Northeastern because I could get more help from the Department of Handicapped Services. This enabled me to take several courses at the same time. At this point, I got a Touch Talker with Minspeak, a new communication system, which doesn't use a number code; it uses strings of visual symbols.

Later I got a DEC Talk, which is a good quality speech synthesizer with a choice of seven voices. I am still learning to use this system. It has a large vocabulary. It has a core vocabulary of over a thousand words that I can use to generate sentences. I can put up to two thousand ready-made sentences into it. I push strings of two or three symbols which access the vocabulary or sentences. It takes a great deal of time to memorize everything. I work every week with three terrific people in the Speech and Hearing Clinic at Northeastern to learn my vocabulary.

At this point in my life I can make a choice. Either I can stay at home and waste my life or I can go out and try to make the most out of it. This means being able to communicate with strangers and learning how to talk for myself. It may not be perfect but it's a good beginning.

Let me tell you what I had to do to get where I am. I never went to school. Between the years of nine and fifteen I had about five hundred hours of home tutoring. I practically taught myself to read. About one year after I got my Handivoice, I met a friend who helped me learn to read. I got my first communication aid through the Massachusetts Rehabilitation Commission. It took me a year to get it. I did a lot of pushing. I kept calling until I finally got it. People tried to put me off. But, it was important to me.

In 1985, I went back to the Massachusetts Rehabilitation Commission because I read a couple of magazine articles about new computer-based communication systems. There were some which would help not only with communication but also with schoolwork. I then want around to a number of organizations to get advice on what sort of system I needed.1 I went to Rehabilitation Engineering Center, which was involved with research. I wasn't too pleased with what they did; they really didn't show me anything. I heard about a group of engineers who would customize aids for individuals not only for communication but also for writing. But, they were never able to help me. Then my counselor at Massachusetts Rehabilitation advised me to go to the Children's Hospital in Boston to see what was commercially available. They showed me the Touch Talker and DEC Talk. I couldn't believe my ears!

There were the usual administrative delays getting everything approved and delivered in time for me to start as a student at Northeastern University in the fall of 1987. However, I have learned a few lessons, persist and persist and persist. I am in my third quarter of my bachelors degree in Psychology.

Now that I am a regular student at Northeastern, I have to do everything other students do. That means lots of reading and writing assignments. It is all that I can do to keep up. My major problem at the moment is writing. My mother bought me an Apple IIc, but my spelling is poor, and my typing is very slow. We are investigating a word processing program developed by IBM which allows me to type in only the few letters of a word and it will predict the rest of it.

Funding for my communication aids has been from The Massachusetts Rehabilitation Commission. Altogether, both my

Handivoice and Touch Talker cost $5,700. That may seem lot a lot of money, but if you put yourself in my position, what would you think?

THE FUTURE FOR LEO LUCAS

My ambition is to work with other severely handicapped people, prescribing communication and writing systems. That's still a few years down the road. I am working with people at Northeastern to establish some directions for myself and to make sure I have the necessary skills before I graduate. Learning the codes for the vocabulary in my new communication aid is a tremendous job. This will continue all the time I am studying, as I learn new technical vocabulary.

I have waited for this opportunity for many years. If there is any way I can accomplish it I will. Technology for some people is a luxury. For non speaking people like me, it is the means to a meaningful life.

I hope this committee will assist other people like myself to benefit from the assistive technology which is currently available.

UCPA would like to commend the Chairman and the members of this subcommittee for their interests in expanding federal policy in the area of assistive technology services. United Cerebral Palsy believes well thought out legislation in this area will allow many individuals with severe disabilities to be educated with their non disabled peers, work in diverse business settings and live independently in the community.

The Education for All Handicapped Childrens Act P.L. 94-142

Many children with severe disabilities need assistive technology services in the classroom and at home to benefit from education and related services, but many states deny children these services. States are also unable to evaluate and train students for assistive technology because of lack of personnel. United Cerebral Palsy receives thousands of calls a year from distressed parents asking for help in accessing assistive technology and learning how to use it. We also receive calls from parents who are upset because their children are not allowed to bring their assistive technology devices home with them from school. This is a very disturbing situation for a parent of a child who is dependent on augmentative communication. These parent's have no tool to communicate with their child at home. These parents are also very concerned that their children will suffer further communication difficulties because of limited access to their technology. We, therefore, look to this Committee to clarify that a free and appropriate education under EHA includes assistive technology services for children who need it as part of their individualized education plan.

We are very encouraged by the introduction of The Technology to Educate Children with Handicaps Act S.1586. We believe this legislation would begin to elevate many of the concerns UCPA has about technology coverage in the Education of the Handicapped Act, because it will assist States to develop a statewide delivery system which would allow severely disabled children to receive the assistive technology they need.

The Vocational Rehabilitation Act of 1986 P.L. 99-506

This Committee was instrumental in ensuring that the rehabilitation engineering services amendments were added to the Vocational Rehabilitation Act of 1986. This Committee responded to testimony that demonstrated the important impact rehabilitation technology services have in assisting severely disabled adults to become employed. Yet a year and a half after this important legislation was passed, the Rehabilitation Services Administration has not issued regulations on these amendments or given states any guidance on how to carry out these amendments. We therefore encourage this committee to pass legislation that assist States to build their capacity to provide rehabilitation technology services and implement the 1986 Amendments.

Since World War II, this nation has put a great deal of money into researching and developing assistive technology devices. This year alone NIDRR will spend $16 millions dollars on rehabilitation engineering research. We must now create a Federal system for ensuring that severely disabled individuals have access to these assistive technology devices and services, while building the capacity of states to provide assistive technology under The Education for All Handicapped Children's Act and the Vocational Rehabilitation Act. United Cerebral Palsy Association believes Congress could do this by creating an incentive grant program to assist states in building their capacity to deliver assistive technology services in the home, the classroom, and the workplace.

Competitive Incentive State Grant Program

Five year grants would be awarded on a competitive basis to states for planning and development of a comprehensive statewide system of assistive technology services.

A State's application must include at a minimum:

1) Documented support of the application from the State Education agency, Department of Vocational Rehabilitation, Part H Lead agency, Office of Maternal and Child Health, the Department of Mental Retardation/Developmental Disabilities, State Medicaid agency and the Office of the Governor for interagency planning and cooperation in the delivery of assistive technology services;

2) The establishment of a State Advisory Council on Assistive Technology services. This Council shall be composed of representatives from State agencies which will be part of the interagency planning, organizations which are active in advocating or providing assitive technology services, persons eligible under this Act for services, businesses with an interest in researching, developing and providing assistive technology, and other individuals with an appropriate interest as chosen by the Governor;

3) A description of past and current state efforts to plan and develop a statewide system to deliver assistive technology services;

4) An explanation of such a system that will seek solutions to the problems of accessing assitive technology during transition from early intervention to public education and from secondary education to post-secondary education and adult service systems;

5) A description of a comprehensive training program for parents, professionals across multiple disciplines, and individuals with disabilities to increase their understanding and involvement with assistive technology. Such a training program should include both inservice and preservice components;

6) A description of the priorities and a five year timeline for development of a statewide system which by year:

a) estimates the number of individuals to benefit from assistive technology with increases each year.

b) outlines a projected plan of operation, including development of services delivery system and increasing interagency coordination.

c) describe methods for increasing private sector, not for profit and for profit corporations participation in the delivery of assitive technology;

d) describes the methods for financing and funding assistive technology to increase access for users; and

e) and explains a system of quality assurance.

UCPA recommends an authorization level of ten million dollars to begin to involve states in this competition to achieve permanent system change.

In addition, to the capacity building grant program, UCPA makes the following four additional legislative recommendations.

Federal Leadership

National Assistive Technology Advisory Council

We urge Congress to establish a National Assistive Technology Advisory Council with representatives from the public and private sector. The purpose of this Council would be to review Federal funding policies that our currently impeding the delivery of assistive technology services. The Council would report their findings and recommendations to Congress one year after it is established. As you have heard here today we have many different types of assistive technology commercially available for disabled individuals. But even when disabled consumers know about these devices they are unable to benefit from them because of current federal funding practices. We believe the formation of a National Assistive Technology Council would assist Congress in creating federal policy that would economically allow many more severely handicapped individuals to benefit from what is already available.

Department of Education

We believe in order for a Federal initiative in Assistive Technology services to become a reality, the Department of Education needs staff in each Division of the Office of Special Education and Rehabilitation Services (OSERS) and the National Institute of Disability and Rehabilitation Research (NIDRR). We also believe it would be most beneficial to establish a new Deputy Assistant Secretary position in OSERS to coordinate the Department's assistive technology initiative efforts.

Federal Loan Fund for Assistive Technology Services

United Cerebral Palsy encourages Congress to enact legislation which would create a new Federal Program to assist disabled individuals finance their devices. By creating such a fund Congress would be solving some of the difficulties individuals face in purchasing assistive technology. Such a program could help encourage more states to replicate successful loan programs, as have been established in New York, California, and Vermont.

Public-Private Partnerships in Assistive Technology

UCPA recommends the establishment of a new demonstration program within the National Institute on Disability and Rehabilitation Research (NIDRR) to encourage public private partnerships in assistive technology services. The Director of NIDRR would be able to make grants to and contracts with States and public and private agencies in cooperation with business and industry to:

1) establish or develop new approaches to financing and funding assistive technology; or

2) expand the delivery of assistive technology services that enable infants, children, and/or adults with disabilities to become more independent and increase their interactions with their family and non-handicapped peers.

UCPA recommends an authorization level of ten million dollars to attract private sector interest in this important program.

Tax Credits for Business which purchase assistive technology devices for individuals with disabilities.

United Cerebral Palsy Association encourages Congress to pass legislation introduced by Senators Tom Harkin and Lowell Weicker, Jr. which amends the Internal Revenue Code of 1986 to allow business to deduct the cost of acquiring or modifying any property which is specifically designed to enhance the employability and productivity of a disabled worker.

Currently, Section 190 of the Internal Revenue Code allows businesses to deduct the expenses they incur for removing architectural and transportation barriers facing disabled employees. Thus, the underlying concept of this bill is complimentary to current law.

Conclusion

In summary, whether it be high or low-tech based assistive devices, the major problem that now exists is a persistent and-ever-growing gap between product development and product delivery. The weakest link being the absence of an integrated system of efficient service delivery that joins consumers and professionals to available and developing assistive device technologies.

You may recall that Alice, in the very earliest stages of her adventures in Wonderland, came upon an extremely small entrance to a very lovely garden. "How she longed to get out of that dark hall and wander about, among those beds of bright flowers and cool fountains, but she could not even get her head through the doorway." What poor Alice had to do to enter that garden was truly a distracting experience of potions and cakes and telescopes and tears. All these were fine making for a classic children's tale but they are totally unacceptable to real-live people. And, in a sense Alice's tale does suggest a parallel to the issue of this testimony for we are discussing the dream for greater autonomy ever visible but inaccessible except through tortuous means. Hopefully, today's panels and testimonies will forge an alliance between consumers, professionals and government to find a better way to link disabled individuals to the new assistive technologies that can better their lives.

Senator **Harkin**. Thank you for your testimony.

Next I would call on Al Cavalier. Al, again, your testimony will be made a part of the record in its entirety. Please proceed.

Mr. **Cavalier**. Thank you, Senator.

On behalf of the Association for Retarded Citizens of the United States, I would like to thank you and Senator Kerry for your strong interest in this area, and I would like to thank the subcommittee for the opportunity to speak with you today.

Assistive technology and related services can make significant improvements in the lives of many people who are cognitively impaired, in their independence, their education, their productivity, their leisure, and their full integration into the mainstream of life.

When such assistance is needed, it should be integrated throughout all the relevant areas of their functioning, and throughout their lifetime.

Rather than attempting to coordinate a variety of services that you may believe already exists throughout the country, we believe there should be a strong interest by the Federal Government in assisting in creating those services. In most cases, they do not exist, particularly for people with cognitive impairments.

In other words, not only is there no glue to hold together all the pieces of a nationwide service delivery system that includes assisive technology, but also many of the critical pieces are missing. I would like to mention to you a few of those missing pieces.

Very few assistive devices are currently available right now in the marketplace that address the needs of people with cognitive impairments. We believe research and development on new devices that are responsive to those needs should be supported by the federal government.

An example of such research is a project that the Association is conducting with NASA to develop an ultrasonic bladder sensor for people who are incontinent.

If you cannot control your bladder, you cannot hold a job. Many times, you also cannot get into appropriate educational services.

So if you cannot control your bladder, you are often denied access to a lot of the services that everyone else has easy access to.

The device that we are developing is intended to resolve a problem that some people who are mentally retarded have in learning to be completely independent in toileting; a cognitive problem in making the connection between the sensation of a full bladder and the rest of the toileting sequence that we all learn.

The device was designed for approximately 150,000 people with such cognitive needs: A very small market. However, when devices are more flexibly designed, they can have a much larger play to a much larger user population base, and therefore, be viable in the marketplace.

Because of its flexible design, this device is also applicable to the elderly population.

It now has a potential consumer base of over 5 million American citizens. We believe that if research and development efforts start with more flexible designs to take into account the needs of people with cognitive impairments, they will benefit a much larger segment of the American people.

Senator **Metzenbaum**. I do not quite follow that testimony. You say for those who are incontinent, there is a device—I did not quite follow.

Mr. **Cavalier**. We are developing a noninvasive device, Senator, that basically monitors how full your bladder is through the course of the day.

When the bladder reaches a certain level of fullness that you or a teacher or a parent could specify, an external alarm would be triggered, basically giving a noticeable signal, maybe a slight buzzer through an earplug, an LED on the eye glasses, or gentle vibration. Basically, it would deliver an external signal for something that is happening internally. This would allow a person who is not making the connection with the subtle internal sensation that the rest of us attend to to independently toilet ourselves to detect a signal.

So it basically gets around a learning problem, a cognitive problem. Most people who are mentally retarded learn to be completely independent in toileting, but there is a subset who fail to learn because of that critical step. We have designed and are working on the refinement of a device that gets around that hurdle and, thereby, permits them to participate in other services.

Because it was designed more flexibly, the device can be used by a much larger population than just those who are mentally retarded, particularly a large number of the elderly population, plus advanced diabetics who have neuropathy, and some individuals who are quadriplegic. The message is that one of the critical pieces is there is not available right now in the marketplace enough devices that are flexibly designed to serve a large consumer base.

Another missing piece is accessibility. Many devices are currently on the marketplace that could help people who are cognitively impaired, but they are not accessible. One reason is that their interfaces are too complicated.

And therefore, our people cannot access them. Another reason is that training strategies have not been developed to teach proper use of the devices.

As Teddy Pendergrass emphasized, training strategies are very important, and for our population, they are critical.

A third factor, another missing piece, is adequate personnel preparation. Very few practitioners are trained in how to teach a person who is mentally retarded to use technology for its full value, to get optimal benefits from it.

The assistive technology field has moved very quickly, and many of the therapists in the field are ill prepared to do appropriate assessments and then do prescription of the right device for a person. That is a critical element, not just any device but the right device so you will not be limiting them at a further stage in their development.

Another missing piece that you might have already heard a lot about is information access. There is an information drought about assistive devices and services in most local communities in the country.

The information is available, but again, access to the information is lacking. We believe support by the federal government in facilitating information access would be extremely helpful to a large number of American citizens who are disabled.

It is important to note, though, that information by itself, will be of little benefit without the other pieces of a complete service delivery system in place.

A point that I would like to stress is that our Association has seen ample evidence and believes very strongly that not only does assistive technology benefit the person who is disabled, but in many cases, it also has even greater benefits for the families of the people who are disabled.

And so we would like to stress that eligibility criteria for such assistance should take into account and be sensitive to the benefits that are derived by the families of the people who are handicapped.

I would like to re-surface assessment as another significant piece that often is overlooked.

It is critical for the right device to be applied; that is, that there be a careful assessment done of the individual's needs and of the match up with the available technology, so that the proper prescription can be made.

Eyeglasses might be a good example of this. If an appropriate vision assessment were not done, a person could be very limited and have a new handicap by an assistive device, eyeglasses, that was ill suited to them.

Again, that gets back to the training issue, not just of the individuals who are disabled, but also of the people who are the practitioners in the field. They must be trained in a number of skills, assessment being a very critical one.

Well, I would like to summarize by saying that today's assistive technology provides unprecedented opportunities for citizens who are cognitively impaired, particularly those who are mentally retarded, to achieve their full potential.

The application of technology to people who are cognitively impaired is an area that has been underexplored. I urge you to strongly consider the needs of these individuals.

Thank you.

Senator HARKIN. Thank you very much, Al.

[The prepared statement Mr. Al Cavalier follows:]

arc
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Technology Assistance:
Devices, Techniques, and Services for People with Cognitive Impairments

Testimony
to the Subcommittee on the Handicapped
of the Committee on Labor and Human Resources
of the U.S. Senate

May 19, 1988

Al Cavalier, Ph.D.
Director, The Bioengineering Program
Department of Research and Program Services
Association for Retarded Citizens of the United States

Opening Statements

Children and adults with mental retardation or other cognitive impairments can be more independent in activities of daily living, can learn more in school, can be more employable and more productive when employed, and can obtain more satisfaction and enjoyment in their leisure when provided appropriate assistive devices and strategies for their optimal use. Children and adults with mental retardation or other cognitive impairments are not deriving these benefits from the nation's advanced technology. Products responsive to many of their important needs are not available. For those needs for which products are available, they are not accessible.

The sophisticated use of tools distinguishes us from all other beings in the world. In this context, tools can be looked upon as extensions of ourselves to augment our abilities and compensate for our limitations. Today's technology represents the most advanced and powerful set of tools yet devised. We can transmit our voices instantly across the ocean by pushing a few buttons, regulate the surrounding temperature by turning a dial, and cook a whole meal in a matter or minutes by setting a few controls. All such augmentations and compensations are adaptations to serve our needs, and while most of us take for granted these prostheses, the net result is a dramatic increase in our productivity, efficiency, and leisure. The applications of technology, however, have thus far discriminated against a large number of American citizens. Our technological advances have not been designed with sufficient creativity and flexibility to incorporate the needs of many people who are mentally retarded. Society has yet to produce assistive devices or incorporate assistive features for people who are mentally retarded. It is the belief of the Association for Retarded Citizens of the United States that these advances will not occur without strong leadership from our federal government.

To date, the private sector has been primarily responsible for the few innovations in devices, techniques, and services that are currently available. The Bioengineering Program of the Association for Retarded Citizens was initiated in 1982 to explore the contributions of advanced technology to serving the needs of people who are mentally retarded. The Program has three major purposes: 1) to modify existing devices and to develop new devices that are responsive to the needs of people who have cognitive impairments, b) to research training procedures and techniques that improve the use of assistive devices; and c) to improve the delivery of services that include technology assistance.

In conducting its activities, the Bioengineering Program makes use of a nationwide network of over 1300 state and local ARC chapters, the majority of which are service providing agencies in their local communities. Based on this chapter structure and over 150,000 members, the ARC is the largest voluntary organization in the country devoted exclusively to the welfare of children and adults with developmental disabilities and their families.

Examples of Improving the
Availability of Assistive Devices
for People With Cognitive Impairments

Independence in Toileting

In attempts to normalize the lives of children and adults with mental retardation, much energy has been devoted to teaching these individuals to function independently in society. The problem of incontinence often thwarts the best of these efforts. Successful toilet training depends on the learner recognizing the sensation of a full bladder and then associating that feeling with the toileting routine. For many people with severe and profound mental retardation, this connection between internal state and external behavior is difficult to establish. While toilet training programs are quite effective in teaching some people that routine, these programs typically presuppose that all people are already cognitively aware of those sensations. However, children and adults who are severely cognitively impaired have difficulty detecting these subtle and obscure signals.

Incontinence typically results in a negative stigma for the person, reduced positive interaction with other people, unsanitary living conditions, excessive laundry expenses, and increased custodial attention by caregivers. Because of incontinence, individuals are often actually denied participation in a variety of educational, vocational, and social programs--all of which are critical experiences necessary for their developmental growth and integration into community life.

As a consequence, the ARC Bioengineering Program has been developing an assistive device that allows individuals and caregivers to recognize when the bladder is sufficiently full. The bladder sensor uses ultrasound to monitor the volume of urine in a person's bladder throughout the course of a day and then provides a subtle signal when a specified level of fullness is reached. To accommodate individual needs, the signal can be an auditory, visual, or tactile cue. With the device, individuals can be taught to take responsibility for recognizing the need to urinate, first by relying on the device and then by relying on the internal feeling that comes to be associated with the signal from the device. At the same time that people are being trained to use the device, they should also be learning toileting skills so that they will know the proper routine once they recognize the need to urinate.

The device consists of a small sensor positioned on the lower abdomen that is connected to a "walkman" sized unit in which all the processing logic is located. When the logic unit determines that the bladder has reached the level of fullness specified for an individual's needs, a signal is given to the individual wearing the sensor and, if desired, transmitted remotely to a parent, teacher, or nurse.

The development of this device is funded in part by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education and involves a collaboration with the ARC, the University of Tennessee Medical School, NASA's Technology Utilization Program, and local ARC chapters.

While the device was designed from the outset for the needs of people with mental retardation, sufficient flexibility in adjusting different parameters was also intentionally designed into the device to permit it to be responsive to the largest consumer base possible. As such, the device can also provide increased independence for people who have permanently lost the ability to control their bladders for medical reasons, such as spina bifida, quadriplegia, diabetes, cerebral palsy, and advanced age. An initial market analysis estimates that there are over five million American citizens that could benefit from such an aid. We believe that not only can assistive devices be designed to accommodate the needs of people who are cognitively impaired, but they also can be designed flexibly to address a much larger population and thereby survive in the marketplace.

Improvements in Cognition

While most instructional software packages are based on general educational principles, few are precise translation of well-proven educational procedures. Exact translations are difficult to achieve because they require complex programming: detailed instructions and examples, varying levels of difficulty, motivating rewards, corrective feedback, and sophisticated analysis to individualize instruction to each student. It is important to note that what is being referred to is the transfer of an entire instructional procedure, not just a learning task.

Cognitive process deficiencies represent a critical problem for people with mental retardation and learning disabilities. Many researchers have studied how people process information and have identified ways to remediate processing problems. Unfortunately, the procedures are complex and very laborious and, consequently, are not used by teachers in our nation's schools. We believe these conditions justified attempting to automate the remedial procedures on the personal computers typically found in the schools. This was an important focus, since if it were successful it would achieve gains in the fundamental cognitive skills that underlie all other higher order areas such as reading and mathematics, thereby producing benefits in all of those areas.

With this in mind, the ARC Bioengineering Program, with support from the Office of Special Education Programs of the U.S. Department of Education, designed, developed, and evaluated software to assess the cognitive needs of students with mental retardation or severe learning disabilities and then to remediate them.

The software that was developed incorporates assessment and remedial components along with sophisticated ongoing analyses and opportunities to play an exciting video game. Individual cognitive strategies are trained separately at first. Then students are trained to chain them together. The computer always starts by demonstrating what its wants a student to do and then gradually fades the amount of assistance it provides until the student is performing independently. The software incorporates animated graphics as well as written and spoken instructions and comments. It also responds to inputs other than they keyboard (lightpens and joysticks). These accommodate individual needs and allow the students to interact with the system without taking their eyes from the screen.

Extensive field testing in public schools showed that not only did the software improve the cognitive skills of students who were mentally retarded or learning disabled, but it also refined the skills of students who were not disabled.

We believe today's technology provides the most powerful tools to directly address the cognitive needs of children and adults with mental retardation or other cognitive impairments.

Freedom of Choice and Expression

Persons with profound mental retardation and severe physical impairments often are bed or wheelchair-bound with very limited control over even gross motor movements and often are capable of making only unintelligible sounds--truly a difficult challenge for caregivers and teachers. They are usually totally dependent on others to discern their basic needs such as thirst, hunger, or toileting, and to make choices for them that agree with their desires such as turning on the TV or rolling over. If their needs are not discerned by others, their needs are not met. Often these individuals are denied by their disabilities--and society's response (or lack of response) to them--the social interactions, opportunities for productivity, and personal fulfillment to which everyone is entitled. It is too easy for other people to come to believe they have no preferences and no desires. Parents and other caregivers are also severely impacted by the multiple handicaps in that they are needed to provide extensive care and attention.

People with severe multiple handicaps often appear passive to caregivers, who react by offering few opportunities for active involvement in decision making. Such circumstances typically result in extreme frustration, increased passivity, and helplessness in people with these handicaps. This ironically reinforces the dependency and creates a cycle of diminished expectations. What is needed is a new arrangement of the environment that allows "dependent" people to exercise independent control over various aspects of it. Increased self-esteem and independence for the disabled individual is the result, along with altered perceptions on the part of caregivers.

The ARC Bioengineering Program believed assistive technology might hold the key to such a reversal. The assistive device developed to address this situation was an off-the-shelf computer system with voice recognition capabilities that was linked through newly-developed software and a variety of interfaces to such items as TVs, radios, electric fans, vibration massage pads, and videocassette recorders. While environmental control systems have been used by persons with physical handicaps who are not cognitively impaired, it had never been determined whether someone with profound mental handicaps and severe physical impairments could learn to purposively use such technology or if the benefits of such use would be substantial. The basic intent was to configure a computer-based assistive device to intervene for the subject at his/her choosing to provide some freedom of choice and control over significant aspects of his/her environment.

The subject selected for this investigation was 42 years old, possessed no self-help skills, was completely dependent on others for the fulfillment of all her needs, had almost totally unintelligible vocalizations, and was confined to a bed or gurney chair all of her waking hours--a person representative of most of those who are waiting to be released from institutions. The basic questions were: Could she understand the concept of "control" after never having experienced it in her life and would she use it constructively?

The system was activated entirely by voice. The woman who was disabled needed only to make consistent sounds--they did not have to be real words--in order to turn the appliances on and off at her choosing. Results showed that the woman not only learned the cause and effect relationship between making a sound and activating a device, but she also learned to discriminate among the devices and select only those she cared to operate and only at the times she cared to operate them. She also became much more animated and expressive.

The woman expressed obvious pleasure while using her system and appeared to take pride in demonstrating it to others. Videotapes captured her laughing and exclaiming with delight when she realized her impact on her surroundings by operating the device. She also expressed displeasure when the system was temporarily disabled. She had distinct preferences among the appliances and seemed at times to turn them on and off for the sheer pleasure of being in control.

The woman's caregivers were surprised to observe her newly revealed skills, and began to behave differently themselves. They interacted with her more frequently and encouraged her participation in decisions about her daily routine.

This research shows what is possible with commonly-available computers and peripherals. It demonstrates that people with profound mental retardation, who typically receive the most minimal of services and are the last to be considered for more normalized living routines, can begin to exercise the basic fundamental rights of freedom of choice and expression through advanced technology and skilled training procedures. Hidden capabilities can be unmasked and new skills developed. As the technology continues to be refined and extended, it can also offer to parents, teachers, and therapists optimism that more normalized and rewarding lifestyles are indeed possible for people with severe cognitive impairment.

Examples of Improving the Accessibility of Assistive Devices for People with Cognitive Impairments

Integrating Technology Assistance Into Service Delivery

In conjunction with the ARC, the University of Texas at Arlington has been conducting a three-year effort to design, implement, and evaluate a model strategy for integrating technology assistance into an existing developmental disabilities service delivery system in a large urban community. As part of this effort, the ARC operates a telecommunications network comprised of an electronic mail and bulletin board system to provide information sharing among service providers and consumers and a computerized database of resources on the application of technology for people who are disabled.

Results of these efforts show that a critical factor in an effective community service delivery system that includes technology assistance is the delivery of the services by adequately prepared professionals and paraprofessionals. Easy access to a pool of information is not enough: service providers must be trained to assess a person who is cognitively impaired for the appropriateness of technology assistance, to prescribe the appropriate assistive device, to teach the proper use of the device, and to evaluate its continued appropriateness. A second critical factor is the provision of follow-up support after a consumer has purchased and been using the assistive device for some time. Too often, a consumer is totally on his or her own. A third critical factor is the provision of sustained interaction between consumer and device prior to purchase, e.g. centralized sites where an extensive collection of assistive devices can be "tried on" under skilled supervision and provided on a loan basis for a period of time sufficient to determine the appropriateness of the consumer device match-up.

Strategies More Than Devices

For two years, the ARC assisted the American Speech-Language-Hearing Association (ASHA) in improving the use of augmentative communication aids in the nation's schools by children having little or no intelligible speech. Communication aids range widely in complexity, design, and cost. This study identified 11 exemplary communication programs in the nation. These programs were analyzed to determine why they are successful and how they have dealt with obstacles to providing appropriate communication services. For people with cognitive impairments, once again, a critical factor was shown to be the assessment of their abilities and of the appropriateness of technology assistance by skilled clinicians.

It is important to note that, as in the case of many of the rehabilitation engineers who helped to pioneer the field of rehabilitation technology, many of the early leaders in augmentative communication--who still exert strong influence over the field--have had limited experience with children and adults who are cognitively impaired, are unfamiliar with the skills that they have been shown to achieve, and hold dismal beliefs about their ability to benefit from communication aids. As a result, most communication aids were not designed with interfaces that permit access by these individuals. More creative researchers and clinicians have shown that not only do such aids significantly enhance the ability of children who are cognitively-impaired to speak, but they also represent powerful new tools to teach them language and its functions, thereby permitting them to participate fully in the educational process and beyond.

Recommendations

a) Technology assistance can significantly improve the independence, education, productivity, leisure, and integration of citizens who are cognitively impaired. Such assistance must be integrated throughout all of those areas of a person's functioning and throughout his or her lifespan.

b) Rather than coordinate a variety of technology services that already exist in fragmented fashion around the country, the federal government must assist in the creation of those services. They do not exist.

c) There is no comparison between today's technology assistance and anything we have witnessed in the past. We should not be constrained to adopt existing service delivery models for this new enterprise. We should not rely on old solutions to such novel problems. New systemic design is needed.

d) Very few assistive devices that are responsive to the important needs of people who are cognitively impaired are currently available in the market place. Research and development of new assistive devices that focus on such needs and that are more flexibly designed should be supported.

e) Of those assistive devices that are available for people who are cognitively impaired, most of them are not accessible due to designs that did not take into account cognitive needs, training strategies that have not been developed to teach their use, and practitioners who are ill prepared to assess and train. Personnel preparation, both preservice and in-service, must be a major component of a nationwide service delivery system.

f) Research and development efforts in this new area typically are more expensive and require more time than other research projects. To realize the powerful benefits of technology assistance, we must commit larger budgets and longer timelines for federal projects in this area.

g) There is a prevailing belief among many of the leaders in the field of assistive technology that people with mental retardation or other cognitive impairments are not appropriate consumers of assistive technology. They have had limited or no experience in applying technology assistance to such individuals. They are prisoners of the past whose self-limiting beliefs create self-fulfilling prophecies. People with mental retardation or other cognitive impairments should be named as "traditionally underrepresented groups" with regard to technology assistance; otherwise it will become a further means of discrimination against these groups.

h) Accurate information on the nature and extent of the existing and future market for assistive devices and services has a critical role in the definition of research and development agendas and ultimately the responsiveness of the service delivery system. Demographic studies should be supported, with assurances that people who are cognitively impaired are not excluded.

i) Research on training strategies and procedures to teach optimal use of assistive devices is extremely important for people with cognitive impairment, and should be supported by the federal government.

j) Technology assistance assists the family of people who are disabled as much as, and sometimes more than, the individuals who are disabled. These profound effects must not be overlooked or underestimated.

k) Consumers in many cases need financial assistance in purchasing assistive devices and related support services.

A Concluding Perspective

We are at a very primitive stage in the history of technology assistance. Disabilities need not be handicaps to a person's independence, learning, productivity, leisure, or integration. In too many cases at this point in our history, they are. I have a severe disability. In more primitive times, my independence, my productivity, my enjoyment of life, would have been severely restricted because of this disability. I would have been severely handicapped. Because of an assistive device that everyone long ago has taken for granted, which has become "invisible" because it is so commonplace, this is not the case. If you took away my eyeglasses and then observed how I behaved through the course of a day, you would have no doubt that I was handicapped. Imagine my chances of survival in more primitive times! With the technology of eyeglasses and with its associated service delivery system, I no longer give any thought to my disability. I don't need anyone to do anything for me, and my potential, which was so low without the technology, is now much greater. I am not handicapped.

For children and adults with mental retardation, we are back in those primitive times. With appropriate technology assistance, we can keep their disabilities from becoming handicaps; we can free them to be more independent and productive. Today's technology offers unprecedented opportunities for them to achieve their full potential and enter fully into the mainstream of life. When we are in a less primitive time than now, their assistive devices will draw no more attention and be no less accessible than eyeglasses are today. We can begin to make those strides today.

Thank you.

Senator **Harkin**. Our next witness is Carolyn Rossick, representing Rocky Stone, founder and director of Self Help for Hard of Hearing People Inc., an advocacy and information organization for hard of hearing people.

Carolyn, welcome to the subcommittee again. Your statement will be made a part of the record, and please take five minutes or so to summarize your testimony.

Ms. **Rossick**. Thank you, Senator.

Good morning, Mr. Chairman, members of the subcommittee, ladies and gentlemen, my name is Carolyn Rossick, and I am both a staff member and a hard of hearing individual who works with Rocky Stone.

I am going to read his testimony because he is unfortunately unable to be here today.

My name is Howard E. Stone. Most people call me Rocky. I am a profoundly deaf, 110-decibel loss, hard of hearing individual. But with the aid of assistive listening devices and good speech reading skills, I manage to function as a hard of hearing person in the hearing world.

I am the executive director of Self Help for Hard of Hearing People, Inc., and attached to our comments are literature about the organization.

Today, I would like to take a moment to demonstrate how assistive technology has contributed to changing life circumstances for me personally, and by extension, how it could change the lives of millions of other persons with disabilities.

At the age of 19 I became severely hearing impaired. Nevertheless, I was able to acquire a good education, and experience a satisfactory career.

At age 49, I became profoundly deaf, and the telephone was denied to me. In 1975, I retired at the age of 50.

As assistive listening devices, ALDs, developed from 1978 and beyond, I began to find improved ways of coping with my hearing loss, and of remaining in the mainstream of the hearing world.

Induction audio loops, infrared systems, and radio broadcast AM and FM systems, became available to the individual consumer in the 1980s.

They gave me a new lease on life. Although the method of sound delivery differs, all of these systems operate on the principle of improved speech-to-noise ratio.

They take the speech directly from the speaker, and through the use of a microphone, they transmit that sound directly to a system that a receiver and a listening earpiece can use.

This eliminates background noise, reverberation, and distortion, which makes it difficult for a hard of hearing individual to participate in conferences and meetings.

My hearing aid, in contrast, only receives speech after it has travelled through the space separating you from me, and the amplified hearing aid picks up whatever noise might be in that space.

Hearing impaired persons often can hear the sound of speech but cannot understand it. Assistive listening devices go beyond the hearing aid, and permit persons like me to function in circumstances where previously we could not.

I am on several boards of directors, the VA merit review panel, several research advisory boards, and several consumer advisory boards. Most have over 25 members.

I take this FM system with me, and either place the transmitter in the center of the room, or ask a speaker to hold it six inches or so from their mouth, and I wear this receiver. Without it, I could not function in business meetings or hear at the hearings today.

I am scheduled to travel more than 75,000 miles this year. When I stay at a hotel, I cannot hear a door knock, a telephone ring, or a fire alarm.

Although the private sector is gradually responding to these needs, I cannot yet rely on them. I carry a visual alert system with me.

By simply plugging in the device, and attaching a transmitter to the door, I can be alerted by a flashing light that there is someone at the door, a ringing telephone or a smoke or fire alarm going off.

Too often in the past, I have been writing or reading in my room, only to find out later that the building had been vacated in a fire or bomb threat while I serenely went about my business.

The visual alert system offers me safety and peace of mind as well as the ability to answer the phone or the door. It can also be used to wake me up in the morning.

Similar devices are designed to be used in the home.

Although I cannot carry on a conversation on the phone, I can structure my calls in a way to successfully complete two-way communication of some messages. To enable me to do this, I carry a small device which slips over the earpiece of the phone and amplifies the voice of the speaker.

Most importantly, it also provides hearing aid compatibility to any telephone which is incompatible.

In the office, I frequently use a TDD, which is called a telecommunications device for deaf people.

My church is equipped with an audio induction loop which is used in conjunction with hearing aids that have a telecoil.

I watch television with closed captions and enjoy it. Prior to current levels of captioning, I did not enjoy television viewing.

Another option available is the use of infrared light to transmit sound from the speaker of a TV set to a receiver that can be worn by the individual listening in.

Mr. Chairman, I have been describing usage of technology. But more importantly, I have been describing how a person who is disabled can continue to contribute to society.

SHHH would not be where it is today, helping change thousands of lives for the better, if I did not know about and have access to this technology.

Demographics show us the future need to keep competent persons on the workforce longer, as our labor reservoir of young persons shrinks. Yet older persons are losing their hearing faster than ever before. Because of lack of knowledge or access to assistive technology, by themselves, or by their employers, many are being forced out of their jobs or are relinquishing them voluntarily.

Mr. Chairman, the proposed legislation will develop awareness, permit access and bring all elements of society together in a focused effort to improve the contribution of persons with disabilities to the work force, in their communities, to their families and to themselves.

It may even reduce the requirement for me and for others like me to carry a suitcase full of gear where I go.

It is legislation truly worth of our unstinting support.

Thank you and your committee for inviting me to share my experience with you today, and thank you, Senator, for allowing me to speak on behalf of Rocky Stone.

Senator HARKIN. Carolyn, thank you very much for your fine testimony.

[The prepared statement of Mr. Stone, with an attachment, follows:]

STATEMENT

BY

HOWARD E. STONE, SR. (READ BY CAROLYN ROSSICK)

REPRESENTING SELF HELP FOR HARD OF HEARING PEOPLE, INC. (SHHH)

BEFORE

SUBCOMMITTEE ON THE HANDICAPPED

UNITED STATES SENATE

ON

ASSISTIVE TECHNOLOGY FOR PERSONS WITH DISABILITIES

MAY 19, 1988

Good morning Mr. Chairman, members of the Subcommittee, Ladies and Gentlemen. My name is Carolyn Rossick. I am going to read the testimony by Howard "Rocky" Stone who is unable to be here today.

My name is Howard E. Stone. Most people call me "Rocky". I am profoundly deaf (a 110db loss in both ears), but with the aid of assistive listening devices and good speech reading skills, I manage to function as a hard of hearing person in the hearing world. I am the Executive Director of Self Help for Hard of Hearing People, Inc. (SHHH). I will attach literature describing our organization to my testimony.

Today, I want to demonstrate how assistive technology has contributed to changing life circumstances for me personally, and, by extension, how it could change the lives of millions of other persons with disabilities.

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As assistive listening devices (ALDS) developed (1978 and beyond) I began to find improved ways of coping with my hearing loss and of remaining in the mainstream of the hearing world. Induction (audio) loops, infra red systems and radio broadcast (FM and AM) became available to the individual consumer in the 1980s. They gave me a new lease on life. Although the method of sound delivery differs, all of these systems operate on the principle of improved speech to noise ratio. They take speech directly from its source into the listener's ear, thus eliminating most background noise. My hearing aid, in contrast, only receives speech after it has travelled through the space separating you from me, and the amplified hearing aid picks up whatever noise might be in that space. Hearing impaired persons often can hear the sound of speech but cannot understand it. ALDs go beyond the hearing aid and permit persons like me to function in circumstances where previously we could not.

I am on several Boards of Directors, the VA's Merit Review Panel, several Research Advisory Boards and several Consumer Advisory Boards. Most have over 25 members. I take this FM system with me and either place the transmitter in the center of the table or ask the speaker to hold it six inches from his or her mouth. I wear this receiver. I could not function without it.

I am scheduled to travel more than 75,000 miles this year. When I stay at a hotel I cannot hear the door knock, telephone ring, or the fire alarm. Although the private sector is gradually responding to these needs, I cannot yet rely on them. I carry a Visual Alert System with me. By simply plugging in the device and attaching a transmitter to the door, I can be alerted by a flashing light to someone at the door, a ringing phone, or a fire alarm. Too often in the past I have been writing or reading in my room only to find out later that the building had been vacated in a fire or bomb threat while I serenely went about my business. The Visual Alert System offers me safety and peace of mind, as well as the ability to answer the phone or the door. It can also be used to wake me up in the morning. Similar devices can be used in the home.

Although I cannot carry on a conversation on the phone, I can structure my calls in a way to successfully complete two way communication of some messages. To enable me to do this, I carry a small device which slips over the ear piece of the phone and amplifies the voice of the speaker. It also provides hearing aid compatibility to any telephone which is incompatible.

In the office I frequently use a TDD (Telecommunication Device for the Deaf).

My church is equipped with an induction loop which is used in conjunction with hearing aids having an induction switch commonly referred to as a "T" switch.

I watch television with closed captions and enjoy it. Prior to current levels of captioning, I did not enjoy television viewing.

Mr. Chairman, I have been describing usage of technology, but more importantly, I have been describing how a person who is disabled can continue to contribute to society. SHHH would not be where it is today - helping change thousands of lives for the better, if I did not know about and have access to this technology. Demographics show us the future need to keep competent persons in the work force longer, as our labor reservoir of young persons shrinks. Yet older persons are losing their hearing faster than ever before. Because of lack of knowledge or access to assistive technology, by themselves or by their employers, many are being forced out of their jobs or are relinquishing them voluntarily.

Mr. Chairman, the proposed legislation will develop awareness, permit access and bring all elements of society together in a focused effort to improve the contribution of persons with disabilities to the work force, in their communities, to their families and to themselves. It may even reduce the requirement for me and for others like me, to carry a suitcase full of gear wherever I go. It is legislation truly worthy of our unstinting support.

Thank you and your committee for inviting me to share my experience with you today. And thank you for permitting me to read Rocky's testimony.

Items demonstrated or shown:

FM listening system
VAS - Visual Alert System
Amplifier - compatibility device
TDD
Induction loop - picture
Closed captioning - picture

Attachments: SHHH fact sheet
Brochure*
Journal*

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*Note: In the interest of economy, these documents were retained in the files of the committee.

SHHH
SELF HELP FOR HARD OF HEARING PEOPLE INC
7800 WISCONSIN AVENUE
BETHESDA MARYLAND 20814
(301) 657 2248 (V) 2249 (TTY)

SHHH
FACT SHEET

SEPTEMBER 30, 1987

* More than 25,000 persons have joined SHHH since 1980.

* 220 chapters and groups are meeting in 43 States, with more continuously forming.

* Members in 17 countries including two National Offices (USA and Australia) and an affiliation in Canada.

* 10 full-time paid staff with a full-time volunteer Executive Director. 3 part-time paid staff.

* 16 States where OPERATION SHHH is being implemented. (Anti-Noise/Hearing Conservation Program for Children).

* 218 SHHH volunteers working in 135 nursing homes in 42 States and Canada.

* Shhh, A Journal About Hearing Loss, published bi-monthly in 43,000 copies and over 200,000 readers.

* Large print edition of Shhh in process. (Funding required)

* Extensive publications list from which to learn about many aspects of hearing loss, its complications and possible accommodations.

* Two international conventions held with two more in process (1988, Rochester, N. Y. - 1989, Bethesda, Maryland - Tenth Anniversary celebration).

* Training programs, workshops and conferences--an ongoing experience.

* SHHH travel tours geared for hard of hearing people.

* Working closely with major organizations involved in the problem of hearing loss.

* Assistive Listening Devices Demonstration Center.

* An inventory of places with assistive listening systems (PALS) in the U. S. Some 20,000 PALS are located in places of worship, theaters, community centers, libraries, etc. and allow hard of hearing people to participate in events not otherwise accessible to them. Upon request, hard of hearing travelers will be provided information about PALS at places in their itinerary.

* Distinguished Service Award for 1987 from American Speech-Language-Hearing Association.

Senator **Harkin**. And last, we have John C. De Witt.

Mr. **De Witt**. Good morning, Mr. Chairman, and members of the subcommittee.

That is by way of a trick, of course, to introduce the fact that I use a lap top computer with synthetic speech.

I appreciate the opportunity to be here this morning, and our written testimony is already a part of the record, I believe.

Senator **Harkin**. Yes.

Mr. **De Witt**. We hope that we will be able to revise and extend those remarks as a result of today's hearings and the new draft legislation which has been circulated recently.

In addition to my activities with the National Technology Center of the American Foundation for the Blind, I am also chairperson of the Information and Technology Division of the Association for Education and Rehabilitation of the Blind and Visually Impaired.

In that division, we are particularly concerned with personnel preparation, and with professional development of persons involved in assistive technology throughout the country. We are concerned with issues of personnel preparation, as I said, accreditation, developing standards of performance for assessing the needs of visually impaired persons, choosing the appropriate device, and training people on those devices.

I am also a member of the Consumer Advisory Group for AT&T's National Special Needs Center. This consumer advisory group, which includes persons with disabilities, has played a major role in guiding the company towards developing products and services for persons with disabilities, and I think it is a shining example of how private industry can also help to work with persons with disabilities in their particular area. I hope it is a model which will be followed by others, and will be fostered by whatever Federal or State initiatives that are put forth.

At the National Technology Center, we provide evaluations of products designed for use by blind and visually impaired persons. We have a major information collection and dissemination system, a clearinghouse on products, and training facilities, funding sources, and so on, for products that blind and visually impaired people can use.

One of the interesting parts of that data base system I would like to tell you about very briefly is what we call our user network. It is a collection of interviews that we did via the telephone from people who volunteered to tell us about what kinds of technology-related devices they use. They are electronically based devices, everything from talking clocks and talking calculators, or perhaps only a cassette recorder to read Library of Congress tapes, up through sophisticated computer systems.

It is astounding that among the general population of blind and visually impaired persons who are of working age, only 34 percent are working. However, among the 903 persons of working age in the NTC User Network data base, 82 percent are working. There appears to be a relationship between use of adaptive technology and employment. So it is obviously of some interest that the people who are using the technology also seem to be the people who are employed.

They are using over 1,600 different products. Now, not all of those are adaptive technology. Some of them are commercial software and computer systems, but over 9,000 products in all are being used, an average of about nine per person.

We know from this data base that 62 percent of the people do use computers, and of them, 80 percent use them five days a week, and a great many of them use them seven days a week. There is a lot of other interesting information that we summarize in our written testimony.

We know for example that there is a man who used to work in a sheltered workshop. He is blind, a college graduate, but now through the use of computers with synthetic speech and with Braille output, he is able to work and is working for IBM.

We know of a man who was a criminal lawyer doing courtroom practice who, with the use of large print displays in his office, is able to read the LEXIS data base information, and through the use of a tape recorder similar to courtroom reporters, with a stenomask, is able to tape his comments in the courtroom without having to be distracted by some other kind of higher tech device.

I take notes with the lap top computer I have in front of me. He has another technique. There are different kinds of technologies which will work for each individual situation.

So, obviously technology is a very important tool. I have to sidetrack for a moment. I remember seven years ago when I first testified before a Congressional committee—in that case it was a House Telecommunications Subcommittee—I laboriously prepared my testimony with my Perkins Braille Writer.

Now, if you know anything about Braille, you know you cannot erase Braille with an eraser; it does not work. You cannot make deletions and insertions and move blocks of text around. It is a mess. And so, I would type out my testimony in Braille, then I would move over to the typewriter, where I could not see what I was typing. I am a touch typist—a lousy one, but fast. I typed it out and of course made lots of mistakes. My secretary then read it back, we made revisions. Then she retyped the whole thing, brought it back and reread it to me again. I helped her revise it again, and eventually, a sighted Braille transcriber would put it into Braille so that I would have the copy in front of me when I wanted to use it. Very laborious, and it involved the use of two other people to help do it.

The way I prepared this Braille copy was very simple. I sat down at the computer, which is using both synthetic speech and large print. I typed it out, I revised it, I worked it over a little bit here and there, I printed it out in ink print, and I used a Braille embosser to Braille it.

You can see that computer over in the exhibit area. It is the one I actually use in my office. You are all welcome to come and have fun with it. In fact, I have a little game on it that you can use to get a sample of what it is like.

So here I am with the same Braille, but done much faster, without the assistance of as many people. More effective use of my time, and of my employees' time.

While technology, appropriately applied, is obviously very important for people in all phases of their lives at all ages, and for all types of activities, whether it is in school or at work or for personal use, there are still some substantial impediments to getting that technology out to the people who might benefit. I want to give you three single examples which illustrate some of the areas that I feel are most important for us to take a look at.

The first one has to do with planning and coordination within States and between States.

A young woman living in an eastern state gets her education there, and through the State Commission for the Blind, has some training for job readiness. After a little prodding, she was able to get them to give her a closed circuit TV system to use for her classwork.

Following her training, she went out and found a job. Now the job she found was across the State line in another city, a major city where she could find a better paying job.

State number one, her home State, closed out her case. She is employed; case closed; successful rehabilitation—except for the fact that on her job she needed to use a computer, which meant some other kinds of adaptive technology. They would not open up her case in that State because she was now living in a new one.

State number 2 finally opened up a new case after six months, and six months after that, she had her adaptive technology. One year went by, during which time she was not as productive for her employer as she might have been. She had less self worth and overall, it was not a good situation.

Better planning on the part of the original State might have had them stick with her longer; better coordination between the two States might have made the process simpler.

My second example relates to funding. A woman in a midwestern state which borders Iowa—it is not Iowa, Mr. Chairman—works for the State government. She is a newsletter editor. She is one among several. All of her peers use a personal computer and word processor to do their work. She does not. Her employer says, it is too expensive.

Now, I am not sure whether this was a matter of attitude, or funding; but it turns out to be both. The department head will not approve the computer, or the adaptive technology, which in this case costs less than $1,000.

She goes to voc rehab in the state, and they say, well, you are employed, and your employer says he is not going to fire you, so we cannot do anything.

Then she goes to her bank. She has some money in her savings account to buy the adaptive technology, but she needs a loan for the computer. The bank says, no, we do not want to finance a computer, that does not provide good enough collateral for us.

She goes to an organization specifically in the business of providing loans to blind or visually impaired persons. They provide low interest loans. Well, they will finance the adaptive technology, but they will not finance the computer; that is not their business.

She goes back to the department head and asks, will you please buy the computer? He says, well, look, you were hired under a special hiring program, and we do not think it is appropriate.

She is stuck. What does she do? No conclusion to that problem yet.

Senator **Harkin**. Why don't you give me some further information and we will see what we can do about that.

Mr. **De Witt**. I will, thank you.

By the way, I meant to say earlier that this is a situation where you need the computer (the unadapted technology) in order to have the adapted technology work. Gasoline will not run without the car.

My last example relates to personnel preparation. A shocking story for me, as a professional in this field: A man calls me up, says he is a consultant—I better use that word in quotation marks—from a state Commission for the Blind. He is working on a case for a client who needs some synthetic speech software. He asks me, "will product A and product B work well together?" I said, "product A and product B do the same thing." They are competitive products, but they have the same function. He said, "Oh, I did not know that." It is sort of like asking me if a Ford or Chevy will work together. Well, if you have long arms and long legs and two heads, perhaps so. He did not know what he was doing. The state commission did not know that he did not know what he was doing, and the consumer had potentially a wrong prescription.

Now, these are just single examples of things that I think need attention. Proper personnel preparation is certainly important. Funding is important, and I want to respond if I am asked the question about funding similar to what Senator Metzenbaum asked Senator Kerry earlier about the cost.

We need good information collection and dissemination, but we do not need to be redundant with what we do, and I have some thoughts along that line.

I hope that we will develop, through this legislative process, strong Federal guidance to help small states plan their programs within the small state so that they are well coordinated, but also, that the programs between small states will be well coordinated.

We have a patchwork here. It does not work very well right now. And, I think we need to pay some really strong attention to the idea that the small states need to work better together.

Thank you.

[The prepared statement of Mr. De Witt follows:]

STATEMENT OF THE AMERICAN FOUNDATION FOR THE BLIND

by

John C. De Witt

Good Morning Mr. Chairman and members of the Subcommittee. My name is John De Witt. I am the Evaluations Coordinator for the National Technology Center of the American Foundation for the Blind.

The American Foundation for the Blind (AFB), founded in 1921 through the inspiration of Helen Keller, is a national research and consulting organization in the field of blindness and visual impairment. The National Technology Center was officially established in 1986 to develop, evaluate, and disseminate information about technology benefitting blind or visually impaired persons. One of the Center's many projects is the maintenance of a national user network database, which currently lists about nine hundred blind or visually impaired technology users who have shared with us extensive information about their use of technology.

AFB is pleased for this opportunity to testify today concerning key elements which Congress should address in adaptive technology legislation. My oral remarks will summarize our written statement which will be submitted for the record. Of course, we will continue to be available to this Subcommittee's staff as you consider legislation in this area.

I. BENEFITS AND BARRIERS TO TECHNOLOGY FOR BLIND AND VISUALLY IMPAIRED PERSONS

Mr. Chairman, I am convinced that access to adaptive technology has significant impact on the employability of blind and visually impaired persons. As a person with a visual impairment, I am a user of adaptive technology myself, such as this portable Epson computer which has been modified for synthetic speech output. Greater access to information through technology, as well as the ability to more quickly and accurately communicate in written or electronic form with my colleagues, has made my work easier and more productive. From my experience at the Technology Center, I also know that many other blind or visually impaired people have similarly benefitted from technology. Among the 903 blind or visually impaired technology users currently listed in AFB's technology user's network, 82 percent are employed. By comparison, approximately 66 percent of this nation's blind and visually impaired working age population are either unemployed or are not in the labor force. Of the employed technology users in our network, 62 percent report that they use computers with speech, braille, or large print output, and 80 percent of these computer users further report that they use their equipment from 5 to 7 days a week. A detailed summary of our network statistics is attached to my written statement as Appendix A. Thus, it appears that use of adaptive technology impacts upon both the business and personal lives of our network participants.

Yet, we need to reach countless other persons with not only information about adaptive technology, but also the means to effectively utilize it in all aspects of life. Most blind and visually impaired people are poor. In a 1977 survey conducted by AFB for the National Library Service for the Blind and Physically Handicapped, approximately half of the households containing one or more users or potential users of braille and recorded library service reported household income below $5,000 before taxes. The 1976 Survey of Income and Education of the Census Bureau indicated that 19 percent of visually handicapped men and 33 percent of visually handicapped women lived in poverty, as compared to 7 percent and 10 percent for the population as a whole, respectively.

Thus, although adaptive technology does seem to benefit those who are lucky enough to have it, most blind people are not in an economic position to individually acquire this technology, absent third party financial assistance.

II. BASIC ASSUMPTIONS

Mr. Chairman, as you know, several pieces of adaptive technology assistance legislation have been introduced or are being circulated for comment as draft legislation prior to introduction. We at AFB have reviewed these bills and/or drafts, and find elements of each to be worthy of further study and consideration. We believe, however, that whatever legislation that is ultimately enacted into law is only the beginning of an evolutionary process toward achieving sound public policy relative to how we meet the technology needs of persons with disabilities. The field of adaptive technology is in its infancy, and accordingly, we are still working out satisfactory answers to such questions as: What is the appropriate definition of technology? Who decides what devices and services are necessary? Who pays the bill, and how do we coordinate technology assistance with other programs (such as rehabilitation, education, and the aging service delivery system) both federally, and, within and among the states? How should we provide technology assistance to a person whose disability is not static at various stages of his/her life, to a person who is currently not a student or rehabilitation client, or to an older person whose independence with dignity would be enhanced through the use of appropriate technology assistance?

We should also keep in mind that, just as technology is not the panacea for every problem faced by a person with a disability, so too technology assistance legislation should not be expected to cure all of the ills of the rehabilitation, education, and aging systems.

Technology legislation must also be administratively and politically workable. By this I mean that the administrative structure created by adaptive technology legislation must not be overly complex. The definition of technology, as discussed more fully below, must be broad enough, but not too broad. The system must also take into account cost, and should be relied upon as the "payer of last resort" when other systems cannot or will not provide assistance. Like it or not, cost will play a decisive factor in whether this legislation is enacted into law. The interests of blind and other persons with disabilities are not well served by drafting a statute whose breadth of coverage is exceeded only by its cost.

These and many other questions, Mr. Chairman, are complex (some would say mind boggling). I do believe, however, that together, we can develop an adaptive technology system which encompasses support for:

1. Development of new technologies;
2. Evaluation of existing products;
3. Information dissemination to consumers and professionals in accessible media;
4. Assessment of individuals' needs; and
5. Financial assistance (including cost of acquisition, training and maintenance).

We can make a beginning, Mr. Chairman, but keep in mind that we may have to install a new "logic board" tomorrow, as we learn more about this exciting new field of adaptive technology for persons with disabilities.

The remainder of our testimony will highlight some specific elements to be included in adaptive technology legislation.

III. DEFINITION OF TECHNOLOGY

"Adaptive technology devices and services means devices, together with any adaption if necessary, and/or services designed to apply engineering methodologies or scientific principles to the amelioration of the effects of a person's functional limitations."

This suggested definition is not necessarily the ideal definition for adaptive technology, but is proposed as a starting point for further discussion. We believe that the definition of adaptive technology should relate to those specialized devices and/or services which reduce the impediments associated with a person's disability, and which enable such an individual to ideally perform all major life activities. Adaptive technology should not include medical equipment already reimbursed by other sources, or routinely prescribed, low-cost devices such as ordinary eye glasses. Rather, adaptive technology should relate to the devices and services which a person with a disability may need to overcome the deficits resulting from his/her disability. Thus, a talking glucose monitor which announces its readings would be adaptive technology, but an unmodified version of the same glucose monitor would not be. A talking computer system would be adaptive technology in that the computer is usable to a blind person through the incorporation of speech synthesis. By contrast, devices which are traditionally viewed as medical or cosmetic in nature, such as ordinary prostheses, would not be adaptive technologies.

This approach to the definition of technology seems to us to be a reasonable compromise, since adaptive technology legislation should provide reimbursement for devices or services which are not otherwise reimbursed by third party health care payers or other service delivery systems. A limited definition of adaptive technology will also help to limit the cost of this legislation.

V. DATA COLLECTION AND AGENCY COORDINATION

The scarcity of reliable data concerning disability in this country is an ongoing problem, not only as it relates to adaptive technology policy, but also as it relates to disability programs and services generally. Manufacturers who must decide whether to commit resources to the development and marketing of adaptive technology always ask us about the number of potential customers for their products. Unfortunately, we do not have good answers to these questions, since we don't know much about the characteristics of persons with disabilities in this country. Accordingly, we urge the Subcommittee to examine this issue of data collection very carefully. Although this Subcommittee may not have jurisdiction relative to the National Center for Health Statistics or the Census Bureau, your support of funding for a post Census disability survey and increased research activity on disability by the NCHS would be very helpful.

Technology assistance has been incorporated in a patchwork fashion into a variety of federal and state programs. Any adaptive technology legislation should also include a reporting mechanism (either on a regional or national basis) which would help to insure better coordination of effort between the federal government and the states. It is also important that comparative data relative to demographics of disability and approaches to adaptive technology assistance be collected on a state by state basis. Thus, if one state offers a tax deduction for the acquisition of technology, this information could be shared with other states which might want to replicate such a program.

V. AUTHORIZATION OF NATIONAL CENTERS

Mr. Chairman, we believe that any adaptive technology legislation should authorize funding for national technology research and demonstration centers. Such centers could provide valuable development, evaluation, and dissemination of information services to the disability community. Quite obviously, a person with a disability cannot turn to the latest issue of Consumer's Report to acquire objective, comparative data concerning various speech programs or synthesizers. It is important that the research and findings of these centers be distributed widely in accessible media. Simply providing information in printed form is unacceptable. In addition, although centers should have a specific disability focus in order to better address the unique needs of specific disability types, collaborative projects and sharing of information among centers is essential. For example, developments in speech technology are of value not only to blind and visually impaired persons, but also to persons who are vocally impaired. Developments in "mouse" technology which permits easier direct access to the screen for people with motor impairments may also be adapted to permit direct braille access to the screen for a blind user.

VI. CONCLUSION

The American Foundation for the Blind will be happy to elaborate further on points raised in this testimony. Several other issues remain, however, for further discussion. For example, we believe that professional certification in the field of adaptive technology is necessary, but that development of appropriate standards will be a complex task. We believe that the technology needs of persons with disabilities can be accommodated over a lifetime through innovative approaches such as the recycling of devices, and that acquisitions of technology should not be limited to items contained on a state-approved procurement list.

Thank you for your interest in this important subject. I will be happy to try to answer any questions at this time.

Appendix A

AMERICAN FOUNDATION FOR THE BLIND - NATIONAL TECHNOLOGY CENTER

Statistics for Visually Impaired People in the User Network Database

TOTAL PERSONS REPORTING USE OF "ELECTRONIC" EQUIPMENT:	903	Responses
GENDER:	903	Responses
Male:	537	59%
Female:	366	41%
AGE:	893	Responses
1-19:	14	2%
20-29:	92	10%
30-39:	365	41%
40-49:	192	22%
50-59:	140	16%
60-69:	68	8%
70-+:	22	2%
EDUCATION:	903	Responses
Currently a Student:		
Yes:	82	9%
No:	821	91%
Highest Level Completed:	903	Responses
Graduate Degree:	398	44%
Some Graduate Work:	63	7%
College Graduate:	213	24%
Some College:	147	16%
High School Graduate:	59	7%
Some High School:	12	1%
Grade School:	11	1%
EMPLOYMENT:	903	Responses
Yes:	744	82%
No:	159	18%
COMPUTER USED:	898	Responses
Yes:	554	62%
No:	344	38%
DAYS USED DURING WEEK:	554	Responses
5-7 Days:	443	80%
1-4 Days:	111	20%
HAVE YOU RECEIVED TRAINING ON ANY EQUIPMENT:		
Yes:	387	43%
No:	516	57%

Senator **Harkin**. John, thank you very much. And thank you all for being here, and for your fine testimony.

I would recognize Senator Stafford for questions.

Senator **Stafford**. Thank you very much, Mr. Chairman.

Maybe rather than questions, I would have just an observation or two. A little bit light heartedly, I was impressed by the fact that one voice synthesizer could produce seven different voices.

And it occurred to me that were that available to the Senator from Vermont, I could give the three commencement speeches I have got to give in the new few days by using the same speech and putting it in three different voices.

Mr. **De Witt**. That particular synthesizer, Senator, has a child's voice, a woman's voice, an older person's voice, a younger person's voice. You could do a lot with that.

Senator **Stafford**. I hope my colleagues in the Senate do not get hold of it.

On a more serious note, let me say that when Senator Randolph and I were pushing to enact P.L. 94-142, a number of years ago, in the Senate, we knew that handicapped children were not getting a fair opportunity for an education.

We knew that adults who were handicapped were having a difficult problem also.

But I do not think we had any idea of the advances that technology would take from that time, some 10 or 12 years ago, even until now. And I expect that technology, electronic technology, will move equally fast in the next several years, and that the devices you have been using today will be considered primitive by what will be available ten years from now.

So I think really what you have done for this Senator is indicate to us the importance of seeing that handicapped people indeed have an opportunity to acquire the devices, the electronic devices, that will allow them to lead a normal and productive life.

So for what time remains to me in the Senate I will try to do what I can to push forward in that direction.

Thank you, Mr. Chairman.

Senator **Harkin**. Thank you very much, Senator Stafford.

I would just like to ask Leo, first of all, one question, about something in your testimony where you said, "technology for some people is a luxury; for nonspeaking people like me it is the means to a meaningful life."

And again, I think that is a concept that we have got to start getting through here, Bob. This is not a luxury; is essential for them to lead a meaningful life.

Mr. **Lucas**. I agree completely.

Senator **Harkin**. Again, I tend to think that there is a feeling that, oh, these devices are all nice and fancy and that it is quite a luxury for people to have them.

Again, I think that it would help us in terms of our funding if we could change that concept of it.

Leo, let me just ask you a question. Your story is extraordinary; it is one of courage, and tenacity.

What would you be like today, what would you be doing now, if you did not have this assistive technology? What would your life be like without this technology?

Mr. **Lucas**. [electronic voice] I would still be at home. I would still be at home. I would have no future.

Senator **Harkin**. And if I could make one other observation or assumption. You are now 45 years old. If this technology had been available to you when you were 18, you would obviously have been through school and had that behind you and be far more advanced in your life career than you are now; is that a valid assumption on my part?

Mr. **Lucas**. I agree.

Senator **Harkin**. Thank you, Leo. The first time I saw one of these devices was, a couple of years ago in a hearing here.

How much does that cost, do you know?

Mr. **Lucas**. $5,000.

Senator **Harkin**. And I imagine if we made more of them, the price might come down quite a bit. Thank you very much, sir.

Al Cavalier, again, I've got to admit to you, even as Chairman of this subcommittee, as involved as I am with the disability community, I really had not focused much on assistive technology for the mentally retarded.

What you are telling me is that there are many devices, perhaps new adaptive devices, that can be used to bridge a big gap here.

Why are there not many assistive devices for people with mental retardation? What seems to be the problem here?

Mr. **Cavalier**. There seem to be two sets of problems, Senator. One, there are a number of devices that are currently in the marketplace that could be used by people who are mentally retarded except that their interfaces are too complicated.

If you can recall the first time you sat in front of a computer and tried to use a word processor, you probably took a number of hours or a number of days and maybe even weeks to get up to speed on it.

Well, many times the assistive devices that are currently available assume an intact intelligence, and therefore, their interface is not as simply designed for speed of use and ease of use as it could be.

We are beginning to get better at that, and the designs of some of the devices are now taking into account more of the factors that while not focusing on people who are cognitively impaired, have benefits for them.

For example, communications devices are now focusing heavily on speed, because communication needs to flow in an easy and efficient fashion. Well, often to get ease and speed, you design in features that people who are cognitively impaired can make use of.

A lot of the problem for people who are cognitively impared is the interface. The rest of those pieces that I mentioned are also critically important. Our special education teachers are adept at teaching people who are slow learners how to acquire the same skills that you and I acquire faster.

Well, that same kind of teaching expertise needs to be applied to the behavioral side of technology, it needs to be applied to teaching the proper use of devices.

Senator **Harkin**. In other words, a person with mental retardation might be able to make a rather simple decision, input that simple decision into a device that then would return a fairly more complex solution?

The person may not understand the complex solution, but that person would then know that as long as they input that simple message, that something would happen that they would want to happen.

Mr. **Cavalier**. Yes.

Senator **Harkin**. So that is the kind of interface you are talking about?

Mr. **Cavalier**. Yes, assistance with the deficiency. One of the common attributes of mental retardation is reduced memory functioning, that is memory limitations.

Well, computerized aids are very strong in memory and strong in logic; in fact, those are the hallmarks of the microprocessor-based devices. Many times individuals with mental retardation know how to do tasks in an employment setting that are very involved. They know each individual step, but often, the sequencing of the steps makes it difficult to complete the task independently. You can have a cognitive prosthetic that could assist their memory for the proper sequencing.

Our National Employment and Training Program has placed over 35,000 people who are mentally retarded into competitive employment.

Many of them are using some worksite adaptations. You can turn somebody who is unemployed into someone who is productive when they are employed by a small bit of technology that takes into account their cognitive limitations.

Senator **Stafford**. Mr. Chairman, could I be allowed a question here?

Senator **Harkin**. Sure.

Senator **Stafford**. Mr. Cavalier, in spite of the advances of electronic technology today in new devices, many of which can be of very great help to handicapped people, is there a problem in converting electronic machines, so that they can be used by the handicapped because the volume might be fairly low? Is there an economic problem involved there?

Mr. **Cavalier**. In many cases there is. There are problems dealing with the dynamics of the marketplace and that is pretty well true for all disabling conditions.

But as I said previously, if designed flexibly enough, that is, if we focus on the functional need rather than the label of the handicapping condition, these problems can be reduced.

If you are mentally retarded and have a memory limitation, many individuals who have suffered strokes also have memory limitations. If you have difficulty with incontinence, many geriatric individuals have lost the ability to control their bladders.

The functional need often is the same, but the reason for that need may be different. So by designing for those various disabling conditions that have the same functional need, you have a much larger market.

And therefore, the people that need to turn a profit to stay in business to make the devices available now have a viable place.

Senator **Stafford**. Well, thank you very much. Thank you, Mr. Chairman.

Senator **Harkin**. Thank you, Senator.

Mr. De Witt, in your written testimony, you advocate for disability-specific backup centers. We are thinking about adopting that approach, but are also thinking about backup centers that relate to functional limitations, such as education, work, independent living, recreation.

And we are thinking about regional centers that deal with all disabilities.

Just in a few words, can you tell us what advantages do you see in disability-specific centers over other types?

Mr. **De Witt**. You are talking here about information types of centers, or training?

Senator **Harkin**. I think both, information and training centers.

Mr. **De Witt**. Well, I think in terms of information, you have to think of it almost like the spokes of a wheel, or an actual wheel. You have a hub at the center, and from that you radiate out a number of spokes, and you can also have circles intersecting around the spokes.

For example, the information about the lap top computer, which currently is on my lap top, is the same no matter where you are located. I mean, that is information that is national in nature; international, for that matter.

You do not need to have a State government, or a program within the State, gather the same information. That is a redundant effort, and it seems to me, cost inefficient.

So, you can gather information about assistive devices in such a way that it is possible to have one person, or one organization, do it. That could be disability specific at a national level, or it could be done through a networking arrangement between organizations that are based upon regional areas, so that you might have a New England center.

The reason I tend to favor disability-specific is because when you get down to the real nitty gritty about devices, I know only generally about assistive listening devices, but, I know an awful lot about devices that can be used by blind and visually impaired persons. I know a huge amount about large print devices and synthetic speech devices. I am not as strong as one of my colleagues is on Braille devices.

Users or potential users ask us some very detailed questions, and we need to be able to answer those questions fully. We can do so only if we have people who are highly trained in that specific disability area. I think we can do this if we find a way of networking the information.

As far as training centers are concerned, they have to be within States, but the information about the types of training and the types of programs can be shared between States. So that there needs to be networking. I do not think it is a matter so much of how you obtain the information, or how you disseminate it, as long as there is good networking.

Senator **Harkin**. Thank you for clarifying it. That is a good explanation; I appreciate that.

Carolyn Rossick, should the Federal Government help the States to help people like Rocky who has never been a client of Vocational Rehabilitation or any other formal disability service system?

Ms. ROSSICK. I think with respect to the bill, sir, that it would be very important for the Federal Government to oversee something such as John mentioned, in this case, a network whereby one individual living in a remote city in one area knows that by reaching out to the nearby assistive technology center, they can be put in touch with someone on the other side of the country who is designing a piece of technology that might be most appropriate for their needs.

So the way that I see the Federal Government as being effective is by overseeing the States and doing whatever means they can to encourage cooperation between the States, so that you do not have a hangup because you are not a resident of one State, or they cannot have access to the technology that is being developed elsewhere.

As far as funding goes, I think it is certainly important for those individuals who have no other options available to them that there should certainly be a role for the Federal Government to play in providing Federal funding whenever it is absolutely necessary.

In the case of the devices that we are talking about here, the main problem that we have with large area assistive devices is the fact that many of our individuals who have hearing impairments do not know that such technology exists.

They do not have access to a facility that can provide them with information about a wide range of devices that can either—that were either designed with that intent, or can easily be adapted for that intent.

The other problem that they have, sir, is simply that with the stigma associated with the hearing loss, they may know about the technology, but then again, they may not be willing to wear something like this receiver, et cetera, and use it.

But definitely, funding is the third priority of that. So I do think the Federal Government should consider the certain aspects and necessities for people who have no other opportunities for sources for funding of technology.

Senator HARKIN. Thank you. Thank you all very much for your kind testimony.

Now we will call our last panel.

Our last panel for today will present information on service delivery systems for assistive technology. Our first witness is Dr. Martin Fifield, director of the Developmental Center for Handicapped Persons at Utah State University. Dr. Fifield will discuss the personnel issues within existing public and private service delivery systems.

Next, we have Rachel Wobschall, Director of the Minnesota Governor's Initiative on Technology for People with Disabilities, who will discuss the coordination of service delivery at the State level.

Brian McNulty, Director of Special Education with the Colorado Department of Education will then discuss the implications of a statewide service delivery system for special education.

Finally, we will hear from Pete Howell, Director of Program Evaluation for the South Carolina State Department of Voc Rehab, who will present on behalf of Joe Dusenberry, director of Voc Rehab. Mr. Howell will discuss the role of the vocational rehabilitation system in the distribution of assistive technology.

If you would all please take your seats. Mr. Fifield, welcome to the subcommittee. Your statements will be made a part of the record in its entirety; please take about five minutes to summarize it if you would please.

STATEMENTS OF MARVIN FIFIELD, DIRECTOR, DEVELOPMENTAL CENTER FOR HANDICAPPED PERSONS, UTAH STATE UNIVERSITY, LOGAN, UT; RACHEL WOBSCHALL, DIRECTOR, GOVERNOR'S INITIATIVE ON TECHNOLOGY FOR PEOPLE WITH DISABILITIES, ST. PAUL, MN; BRIAN McNULTY, DIRECTOR, SPECIAL EDUCATION SERVICES UNIT, COLORADO DEPARTMENT OF EDUCATION, DENVER, CO; PETER HOWELL, DIRECTOR, PROGRAM EVALUATION, VOCATIONAL REHABILITATION DEPARTMENT, ON BEHALF OF JOE DUSENBURY, DIRECTOR, VOCATIONAL REHABILITATION DEPARTMENT, WEST COLUMBIA, SC

Mr. FIFIELD. Thank you, Chairman Harkin.

Professional colleagues and friends, it is an honor to be asked to testify on the potential of technology to aid those of us with handicaps.

As has been testified here, the growth in technology has touched everyone's life, many times in unforeseen ways. But there are few people who will benefit more from technology than those with disabilities.

We do not know how many people could benefit from the use of assistive technology. Estimates range from between 25 million to about 45 million.

We do know however that this is not a static population. There have been substantial increases in the number of handicapped children reported during the last decade.

Even the number of children with severe limitations has increased over one percent.

Furthermore, the prevalence of disability certainly increases with age. Adults 65 years of age or older are ten times more likely to have a severe disability than those who are under 35.

With the graying of America, we have roughly 12 percent of our population currently over age 65. By the year 2030, that will increase to over 20 percent.

Public awareness and living longer maybe reasons for this increase. But irregardless, we know that the population exists, and technology can help.

Provisions for technology are contained in many pieces of legislation. However, some of these provisions are not compatible.

Eligibility differs. Benefits are not equitably distributed. And obtaining financial assistance has been described as a bureaucratic nightmare.

What current legislation does not do is facilitate a comprehensive approach, either at the Federal or State level. Thus, many of the promises and the potentials are there, but we do not have the means to carry out the planning, coordination, development, marketing, or training, to utilize technology effectively.

A national legislative agenda is needed that identifies the Federal Government's responsibility and stimulates State planning and implementation.

Such recommendation was contained in the 1982 report Technology and Handicapped People of the Office of Technology Assessment. Unfortunately, not much attention was paid to some of the more important recommendations in the report.

In the human service field, the Federal Government has traditionally carried responsibility for research, information dissemination, and manpower training.

In addition, Federal resources have traditionally been used to stimulate awareness, planning, coordination and implementation at the State and local level.

We need such an approach with assistive technology legislation. States differ in their resources, their sophistication, and certainly, the State delivery systems and organizations within States differ.

There must be flexibility in planning and implementation.

I have listed six other reasons in my written testimony. Other witnesses will be testifying about these, so in the interest of time I am going to skip over and talk specifically about the training needs.

First, I want to talk about training needed for providers and advocates, and lastly, the training needed for individual consumers to maximize their utilization of assistive technology.

One of the major barriers in effective utilization of assistive technology is a shortage of trained personnel. Dr. Cavalier testified effectively about that need.

We know there are significant shortages in rehabilitative medical personnel and rehabilitation engineers. But we have even greater manpower shortages at other levels, particularly those skilled in providing counselling, direction, and the technical use of assistive technology.

Assistive technology expertise are desperately needed in a variety of health, education, and social service fields.

Many assistive devices are defined as appliances. They require little training to be used. They are passive, and once they are fitted to the specific needs of the consumer, benefits can be immediately obtained.

These include glasses, hearing aids, braces, many prosthetic devices.

The specialists that provide these generally require licensing or State certification.

Many other assistive devices are defined as tools which require a significant amount of learning on the part of the consumer. The professional expertise needed to select, match, fit, modify, and possibly most important, to teach the use of assistive technology tools, is seriously lacking.

Professional specialization is needed in assistive technology to bridge the gap between technological knowhow and instruction.

To date, that specialization is not well defined. Most people that are performing such a function are doing so out of personal interest. They have learned their skills on the job, usually as team members, sharing expertise and experience. Seldom have they had preservice training, or supervised experiential experiences.

Currently, the training that occupational therapists, physical therapists, communicative disorders personnel, special educators have in assistive technology is very limited.

Informal contact with many of these people have indicated that many have gone through their training with virtually no experience in utilizing assistive technology, or working on interdisciplinary teams.

A Federal manpower training effort is needed to address this problem. Model preservice and in-service programs need to be designed, replicated and disseminated.

A specialization in assistive technology should be built on a professional's home discipline, but added to that should be the principles of teaching. Federal grants for curriculum design could do a great deal in this area and help define some of the quality assurance standards that are needed.

In our human service system, primary providers—the people who provide direct care or case management—are very pivotal. Any system that hopes to adequately address the needs of assistive technology must rely extensively on primary providers.

As primary provider I am including teachers, nurses, case managers, and many paraprofessional personnel. Without the upgrading of the primary provider about assistive technology, our efforts will continue to be fragmented.

Those of us that have benefited by technology will continue, just because we are persistent enough to find out where the information is, and we learn how to circumvent the more traditional service systems, but this will not reach very many people in need.

Senator Kerry's discussion on the need for clearinghouse activity is desperately needed. Efforts have been taken in this direction, but certainly not to the extent that is needed.

We need a composite resource, something like the Physicians Desk Reference on pharmaceutical, or the Buros' Mental Measurement Yearbook, on psychological testing, that provides description information, costs, weaknesses, modification standards, and the training needed to utilize technological devices.

Such a referendum could be disseminated to consumers and providers. It would also serve as a training curriculum central reference.

The second component desperately needed is model preservice and in-service training for curriculums for primary providers. We need model training programs to inform teachers about the availability of technology, and how they can link the needs of clients to assistive technology.

Course requirements need to be built into professional training programs. These need to be added to our certification and our licensing requirements. We also need to look at the in-service training for people who are already in our service system, and for recertification and renewal of professional licenses.

Course requirements in assistive technology is needed.

Training is the primary mechanism of dissemination. Research, awareness campaigns, even financial incentives will fall short of their promise if equal attention is not given to training.

No human service can be any better than the training of those who provide the service. Resources that are invested in training is like seed money, it pays off and pyramids over the years with quality cost-effective services.

Many technological aids cannot be used effectively unless there is appropriate therapy or training.

Sometimes therapy is discontinued when an assistive device is provided. In many instances, consumers need training in how to operate and how to use devices effectively.

Consumer training should be addressed very clearly in the research and development stage of any assistive device. We must then be able to invest in the professsional time of personnel to provide followup and technical assistance.

One of the most exciting areas of technological advancement over the past few years has been educational and instructional technology. Yet comparatively little effort has been made to bring together assistive technology and educational technology.

Well designed self instructional programs could be developed and distributed with an assistive device as a very cost-effective method of addressing consumer training needs.

The application of instructional technology and educational technology has a great deal of promise, both as an assistive device in its own right, and also as a vehicle to address the training needs of assistive technology.

Currently a great deal of the assistive devices are sitting on shelves unused. Perhaps such devices were not designed to meet the needs that they were intended to meet.

However, in many cases, the consumer did not receive the training necessary to use the device meaningfully.

Unused technology represents a bad match between need and benefit, and it is a poor investment.

As the Congress considers assistive technology legislation, I urge thoughtful consideration of a comprehensive approach which includes expanded effort at the Federal level, not only for research and development, but also, for the training and dissemination needs.

Senator **HARKIN**. Thank you very much for a very fine statement. That is one gap that we need to fill. I will get back to that with some questions.

[The prepared statement of Mr. Fifield follows:]

Testimony Submitted to the Senate Subcommittee on the Handicapped

Senator Thomas Harkin, Chairman
Room 430 Dirksen Senate Office Building
Washington, DC

By Dr. Marvin G. Fifield, Director
Utah State University Affiliated
Developmental Center for Handicapped Persons

Introduction

Chairman Harkin, senators, professional colleagues, and friends. It is an honor to be asked to testify as to the value of assistive technology, and the legislative provisions needed to maximize its potential. The rapid expansion of technology during the past several years has touched virtually everyone, often in unforseen ways. However, few people stand to benefit more from technology than those of us with disabilities (Office of Technology Assessment, 1982).

We do not know how many people would benefit from assistive technology (Bowe, 1984). Estimates range from a high of about 45 million to less than 25 million. We do know this is not a static population. Substantial increases in the number of handicapped children have been reported during the past decade (Butler, et al, 1981). Even the number of children with severe limitations has increased over 1%. Furthermore, the prevalence of disability increases with age. Adults over 65 years of age are ten times more likely to be severely disabled than those under the age of 34. Whereas only 12% of our population are currently over the age of 65, that percentage may raise to 20% or more by 2030 (Williams, 1987; Futurist, 1986). Whether this growing number of handicapped children and older Americans reflects a heightened public awareness or the fact that we are living longer has not been objectively established (Behney, 1986). Irregardless of the reason, we know the population exists and assistive technology can help as we pursue independence and full participation as members of society.

Provisions for assistive technology are contained in many legislative acts. Part G of the Education of the Handicapped Act is devoted entirely to expanded use of technology. The 1986 Rehabilitation Amendments contain several provisions for expanded use of technology. Section 204(b) provides a demonstration program to initiate orphan technology development and Section 508 provides for electronic office equipment accessibility. Assistive technology is referred to in the Developmental Disabilities Act, and several other pieces of legislation address important dimensions of the application of technology to improve the lives of individuals with disabilities. However, some of these provisions are not compatible. Eligibility differs, benefits are inequitably distributed, and obtaining financial assistance has been described as a bureaucratic nightmare.

What current legislation does not do is facilitate a comprehensive approach at either the federal or state level for the utilization of assistive technology. Thus, though the promise and potential is great, the means to carry out the planning, coordination, development, marketing, and training for the utilization of technology is fragmented and lacking.

A national legislative agenda is needed that identifies the federal government's responsibility, and stimulates state planning and implementation of assistive technology services. Recommendations leading to such a national agenda were contained in the 1982 report Technology and Handicapped People by the Office of Technology Assessment. Unfortunately, little has been done to implement some of the most important recommendations in this report.

In human services, the federal government has traditionally carried primary responsibility for research, information dissemination, and manpower training. In addition, federal resources have traditionally been used to stimulate awareness, planning, coordination, and implementation of needed services at the state and local level. Such an approach is needed for new assistive technology legislation. Since states differ in resources, sophistication, and organization of service systems, they need planning and implementation flexibility. But the ultimate objective should be the development of a comprehensive, interservice agency assistive technology approach at the state and local level.

The need for such a comprehensive approach is further underscored by several factors:

1. In 1980, it was estimated that over $10 billion a year was spent on health care research. However, less than $1 billion was spent for disability related research, and only a small amount of the $1 billion was devoted to research and development in assistive technology (Office of Technology Assessment, 1982, p. 60).
2. Currently we have little coordination between government supported assistive technology research and that of the private sector. The responsibility for coordinating and integrating efforts to discover and apply advancements in technology to benefit the handicapped is lacking (Office of Technology Assessment, 1982).
3. Awareness and dissemination of information on the availability of assistive technology is not coordinated. The information that is disseminated tends to focus on specific disabilities or specific services.

4. Financial support for the acquisition of assistive technology is complicated by differences in eligibility, marketing, and funding patterns (Office of Technology Assessment, 1982; Scadden, 1987).
5. There has been limited effort to train providers, case managers, and advocates about the availability of assistive technology and how it can be accessed (Enders, 1987).
6. Most efforts to date have given insufficient attention to the training and assistance needed by individuals with disabilities to maximize the utilization of assistive technology (Vanderheiden, 1987).

Training and Technical Assistance

Other witnesses will be testifying about the value of technology, financial barriers, distribution, and model service delivery programs. I would like to focus my remarks primarily on the needs for training -- first on training needed to prepare providers and advocates, and lastly on the training needed by individual consumers to maximize their utilization of assistive technology.

One of the major barriers to expanding the utilization of assistive technology is the shortage of professionals in key disciplines (Office of Technology Assessment, 1982, p. 180). The few studies that have been reported suggest there will continue to be a substantial shortage of professionals at all levels who have the skills to provide counseling and direction in the use of assistive technology. The shortages of specialists in rehabilitation and rehabilitation engineering are well documented, but this is only a small part of the problem. New assistive technology expertise is desperately needed by a variety of health, educational, social service, vocational rehabilitation, and professionals in services to the aging.

Assistive devices that are appliances often require little training in their utilization. Appliances are passive and once adapted to fit the specific needs of the consumer, benefits can be immediately realized. Appliances include glasses, hearing aides, braces, and many prosthetic devices. Specialists needed to provide appliances are generally required to meet specific licensing or state certification requirements.

Other assistive devices are tools which require a significant amount of learning on the part of the consumer. The professional expertise needed to select, match, fit, modify, and teach the use of assistive tools is seriously lacking (Rodgers, 1985).

Assistive Technology Specialization

A professional specialization is needed in assistive technology to bridge the gap between technological know-how and instruction. This specialty should include knowledge of the availability of assistive devices, how to adjust and adapt them to the individual needs of the consumer, and to design and conduct training to teach the consumer technology utilization.

To date, this specialization is not well defined as a training area. Persons performing these functions do so out of personal interest, with skills learned through on-job experience, often working as team members, shared expertise, and experiences. Seldom do staff with assistive technology assignments have specific training or supervised experiential opportunities to develop the combination of skills needed. Currently training in assistive technology for occupational therapists, physical therapists, communicative disorder specialists, special education, rehabilitation counselors, etc. is limited (Vanderheiden, 1987). Consequently, most professionals know something about, but are not sufficiently skilled to work with assistive technology. Special training is needed in how to work as a team member with interdisciplinary techniques and various funding mechanisms.

A federal manpower training effort is needed to address this problem. Model preservice and inservice programs need to be designed to provide a focus in specialization on assistive technology for OTs, PTs, special educators, communicative disorder specialists, rehabilitation counselors, etc. To the extent possible, model training programs should be designed to be replicable. This would facilitate wide dissemination with content flexible to accommodate new advances.

A specialization in assistive technology should build on the professional's home discipline and supplement it with scientific-based technical know-how and the art and principles of teaching. Federal grants for curriculum design and development would facilitate addressing this manpower need and assist in defining quality assurance standards.

Training for Primary Providers

In our human service systems, the primary provider with direct care or case management responsibilities is pivotal. Any system that is to adequately address the needs for assistive technology must rely extensively on primary providers. Primary providers include teachers, rehabilitation counselors, case managers, therapists, and some paraprofessionals who interact and provide direct services to individuals with handicaps. Without the upgrading of the knowledge and skills of primary providers about assistive technology, our efforts will continue to be fragmented and available only to consumers who are persistent enough or sufficiently knowledgeable to circumvent the more traditional service system.

A federal training initiative is needed focused on at least two significant dimensions:

1. A clearinghouse activity is needed to bring together information about available assistive technology. A composite resource like the Physician's Desk Reference for pharmaceuticals or Buros Mental Measurement Yearbooks for psychological testing would be particularly helpful. Such a resource could contain descriptive information including costs, where devices can be obtained, strengths and weaknesses, how they can be modified and adapted, how they have be successfully utilized, the amount of training and type of training needed, standards of safety and quality assurance used in development along with where additional information can be obtained.

   This information, if designed into databases, could easily be upgraded and widely disseminated. Such a reference would not only help consumers and providers to know what is available, but could serve as a central reference upon which to build an effective training curriculum for providers.

2. The second component is the development of model preservice and inservice training curriculums for primary providers. Model training programs should be designed to teach the skills necessary to use available resources which will link the needs of clients with agencies where assistive technology can be provided. Training courses and classes in assistive technology may need to be designed specifically for teachers, therapists, counselors, and allied health personnel.

Such course requirements should be added to professional training standards and certification and licensing requirements.

Model personnel training programs are also needed for inservice training of primary providers currently working in our service systems. Assistive technology training should be a requirement for re-certification and renewal of professional licenses.

Training is the primary mechanism of dissemination. Research and development, awareness campaigns, even financial incentives will fall short of their promise, if equal attention is not given to training. No human service program can be better than the training of those who provide the service. Resources invested in training is like seed money. The payoff pyramids over the years with quality and cost effective services.

Training for Consumers

Many technological aides cannot be placed effectively without appropriate therapy and training. Yet when a client is provided an assistive device, therapy is sometimes discontinued. In many instances, consumers need training not only in how to operate the aide but also how to effectively use it to meet their needs (Vanderheiden, 1987). Sometimes in our desire to make technology available, we overlook the attention that is needed to train consumers to use it effectively. Consumer training should be addressed during the research and development stage of an assistive device. We must then be ready to invest professional time to ensure that the client does learn how to use the technology and then follow up with technical assistance as needed.

One of the most exciting areas of technological advancement over the past few years has been educational and instructional technology. Yet comparatively little effort has been made to bring assistive technology and educational technology together. Well designed self-instructional programs could be developed and distributed with an assistive device as a cost efficient method of addressing consumer training needs. The application of educational instructional technology advances has promise both as an assistive device in its own right and as a vehicle to address the training needs in assistive technology utilization.

Currently, many assistive devices are sitting on shelves unused. Perhaps such devices were not designed to adequately meet the needs intended. However, in many cases, the consumer did not receive the training necessary to use the device in a meaningful way. Unused technology represents a bad match between need and benefit and a very poor investment.

As the Congress considers assistive technology legislation, I urge thoughtful consideration of a comprehensive approach which includes expanded effort at the federal level, not only for research and development, but also for training and dissemination.

I thank you.

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Senator HARKIN. Rachel Wobschall, Director of the Minnesota Governor's Initiative on Technology for People with Disabilities.

Ms. WOBSCHALL. Thank you, Mr. Chairman.

On behalf of the Governor's Advisory Council on Technology for People with Disabilities, I appreciate the opportunity to testify on Minnesota's efforts to provide technology to those who need it.

In October, 1985, our Governor, Rudy Perpich, created a task force to investigate the potential of technology to improve the quality of life for Minnesotans with disabilities. His action was based on the conviction that thousands of people with disabilities could be more independent, productive, and integrated members of society through the use of technology that already exists, or that has the potential to exist.

Based on the recommendations of this task force, the 1987 Minnesota State legislature appropriated funds to create the Governor's Advisory Council on Technology for People with Disabilities.

The council is responsible for the development of public policy, the promotion of technology utilization and development, and greater public awareness regarding the potential use of technology for people with disabilities.

My testimony will be divided into three sections that will demonstrate the rationale for developing a coordinated statewide assistive technology effort, such as the one I direct.

The first section I will talk about will explain the unique expertise that such a body brings to making technology utilization an integral part of each stage of an individual's life.

In the second part, I will outline why a statewide effort is necessary.

And thirdly, I will describe the impact of such programs on individuals with disabilities.

Similar to the interagency councils that might be created by other States for coordination, consultation, and integration of services, Minnesota's advisory council is comprised of representatives of private sector technology producers, service agencies, third-party funding sources, education and library systems.

State agencies that provide services to people with disabilities are also members of this group.

Minnesota's economy has prospered from a strong technology intensive industries and outstanding medical and rehabilitation communities.

Membership on the council reflects these strengths.

One strength of the Federal-State assistive technology bill is to allow each State the autonomy and flexibility to focus on its own unique characteristics in its approach to governing its coordinated effort.

Because providing technology for individuals with disabilities is a unique combination of products, services, training, evaluation, expertise across a broad range of areas is required.

Individuals on our council represent such a variety of experience.

However, regardless of the issue, regardless of our discussions, our focus is always on the individual with the disability, rather than the needs of any particular agency.

Nowhere else in State government do representatives of multinational technology producing companies and service providers sit with individuals with severe disabilities and really listen with the intent of developing appropriate solutions.

Why is a statewide assistive technology effort necessary? Technology is an equalizer that offers the means to compensate for limitations imposed by a variety of disabilities.

It is a tool that can be used in all areas of life—in vocational, educational and recreational pursuits, as well as a variety of daily living situations.

As such a tool, many of which we have seen demonstrated today, this technology needs to be integrated into all areas of service delivery. It is not subject to closure within vocational rehabilitation, to graduation within education, or some other endpoint in services. It is a continuous and rapidly changing process.

Legislation should help States develop a comprehensive strategy in this specialized environment, using the key players that are involved. It is these same key players that then can truly integrate appropriate technological devices and services into their own agencies, programs and businesses.

Statewide efforts are also necessary because of the role elected officials play in public policy, development and funding of these technologies. Many people with disabilities rely on medical assistance or Title XIX of the Social Security Act for assistance in obtaining medical and rehabilitation services.

While there are national criteria regarding eligibility, the States retain considerable discretion with regard to who is served, the scope of that service, and the duration of that service.

In Minnesota and other States, such discretion has prevented the acquisition of some significant categories of technology, such as augmentative communication devices, because such devices do not serve a medical need, even though they provide a very real functional need for an individual who is communication impaired.

The visibility, given Minnesota's council, has stimulated discussion with both public and private sector providers regarding expanded definitions of medical necessity and coverage of technological devices and services.

Our council has found that availability of funding for devices that exist is a pervasive problem. We believe it is the most important barrier to preventing widespread use of technology.

It is critical that States be empowered through appropriation of additional resources to be able to fund the acquisition of technological devices and services for all of its citizens with disabilities.

The real success of such initiatives is measured by the availability and affordability of appropriate technologies and services for people with disabilities.

A significant gap exists between the possibilities offered by technology and the reality of its application.

Legislation that creates the incentive for a coalition of consumers, producers, advocates, and professionals, supplied with funding directed toward the acquisition of assistive technological devices is an important first step in helping States provide technology for all of their people with disabilities.

Senator Harkin. Thank you very much.

[The prepared statement of Mr. Wobschall follows:]

TESTIMONY SUBMITTED
TO THE
U. S. SENATE SUBCOMMITTEE
ON THE
HANDICAPPED

SUBMITTED BY

RACHEL WOBSCHALL
DIRECTOR, GOVERNOR'S INITIATIVE ON TECHNOLOGY
FOR PEOPLE WITH DISABILITIES

STATE OF MINNESOTA,
DEPARTMENT OF TRADE AND
ECONOMIC DEVELOPMENT

May 19, 1988

The members of the Governor's Advisory Council on Technology for People with Disabilities appreciates the opportunity to testify on Minnesota's efforts to advance public policy and private partnerships that make assistive technology available to people with disabilities.

In October 1985, Governor Rudy Perpich created a task force to investigate the potential of technology to improve the quality of life for Minnesotans with disabilities. His action was based on the conviction that thousands of people could have their lives greatly improved by technology that exists or that has the potential to exist.

Over the next six months the task force explored ways to increase awareness for users, the public and professionals; to provide access to appropriate technology based products and services; and to fund research and development that addressed the critical needs in this field. The following is a summary of their findings:

Introduction

In recent years, there has been a tremendous acceleration in the rate of technological innovation, with new devices and processes being developed that can enhance the daily lives and activities of people with disabilities. An enormous range of technological devices is potentially available to help individuals function more fully in areas such as mobility, communication, and the negotiation and control of their environment. Technological advances are also applicable to educational and vocational programs. For persons with disabilities, the availability of assistive devices or technology-related services can mean the difference between employment or unemployment, independent or dependent living, and the ability or inability to participate in the normal, everyday affairs of a community. Action is needed to ensure that technological devices and services are available and accessible to people with disabilities.

Definition and Incidence

A disability is anything that challenges the development or functioning of an individual, such as sensory, physical, mental, or emotional impairments. Accidents, diseases, congenital defects, and aging are the primary causes of limitations to a person's ability to perform one or more important life functions. The limitations imposed by these conditions range from those easily overcome (e.g., wearing eyeglasses to improve visual acuity) to those for which compensation is more difficult or complicated (e.g., the mobility and routine functioning of a person who is quadriplegic).

According to United Nations estimates, more than 400 million people, or 10 percent of the world's population, are disabled. U.S. Census Bureau statistics indicate that there are about 35 million people in the United States who are disabled. In Minnesota, it has been estimated that 14.5 percent of all Minnesotans are limited in one or more functions of daily living as a result of a disability.

Costs to Society

The costs to society of failing to help persons with disabilities to live full productive lives are high. According to national estimates, between 50 and 80 percent of working-age people with disabilities are unemployed. The poverty level among persons with disabilities has increased to 70 percent of families whose heads of households are disabled and earning less than $10,000 per year, as compared to 60 percent in 1975. The resulting cost to society is estimated at $300 billion per year, or $25,000 to $35,000 in lost wages, lost economic growth, food stamps, and medical payments, as well as workers' compensation and unemployment insurance, for each of the 10 million unemployed people with disabilities in the U.S.

Findings

While technological devices and workplace adaptations can be very expensive, companies are finding that these costs are often far outweighed by the cost of long-term disability payments. In addition to savings in wages earned and lowered workers' compensation and unemployment compensation rates, new technological developments can also bring about significant cost savings by helping prevent the occurence of disabling conditions; allowing people with disabilities to live in independent or in semi-independent settings rather than in high-cost institutions; and providing the education and training necessary to enhance the employability of people with disabilities.

A significant gap exists between the possibilities offered by technological devices and processes and the realities of their applications or uses. Some restrictions are purely monetary, resulting in part from the high cost of many technological devices or adaptations relative to functional limitations. Others result from a lack of adequate, available information about technologies for those who could benefit from such knowledge. Still others result from gaps in the process of research and development; that broad area of activity in which needs are identified and products and processes that can meet those needs are developed. All three of these areas must be addressed if disabled Minnesotans are going to be able to fully avail themselves of and benefit from appropriate uses of technology.

A. Information dissemination. Four activities must occur in order for accurate information to be disseminated to appropriate individuals: collection, dissemination, practical application and training. We find, however, that the following is true in Minnesota:

1. There is no systematic effort to gather or disseminate information about existing technologies and their applications. What collection and dissemination is being done is happening sporadically and with no overall coordination.

2. There is no site at which people with disabilities, professionals and concerned others associated with them can have access to equipment in order to assess potentially appropriate uses or applications; and

3. Assistance in selecting and using appropriate devices and processes is not available to all persons with disabilities nor are such services available throughout the state; it is provided only to some in isolated, though excellent, situations.

B. Funding. Financing technological devices and services is an essential prerequisite for their uses. However, current public and private policies and practices are not adequately meeting the funding needs of persons with disabilities, thereby inhibiting their ability to purchase needed devices and rehabilitation services. Specifically, the following problems exist:

1. State agency definitions of key terms, particularly "medical necessity" and "prevailing community standard," are unneccessarily restrictive and therefore prevent or delay full, appropriate uses of technology;

2. Public funding policies do not recognize rehabilitation engineering for conducting assessments needed to select appropriate equipment and to provide training to ensure the full, proper, and safe use of that equipment, and the prior authorization procedure for payments is unnecessarily restrictive; and

3. The definitions of medical necessity used by private insurance carriers that insure the majority of families with children who are handicapped and adults with disabilities are more narrow and more restrictive than those used by public entities. The insurance policies, therefore, do not cover the technologies necessary to remove functional obstacles from the lives of people with disabilities.

C. Research and Development. Introducing new technologies into the lives of people with disabilities is a massive undertaking. Many variables must be considered, such as: the type and severity of disabling condition, the range of specialized technology either currently being used or needing development, as well as the systems and services needed for application. The federal government has a clear role in carrying out and supporting disability-related research and development and setting national research priorities, but their distance from consumers and current funding limitations have diminished the effectiveness of efforts at this level. In many ways, states are in a more appropriate position to address the needs of people with disabilities. In Minnesota, there is at present no consistent effort to do so. Effective disability-related research and development is not taking place in Minnesota because:

1. No effort is underway to identify and document existing technologies and the unmet needs of persons with disabilities;

2. There is no mechanism to disseminate such information to producers and consumers and to encourage ongoing dialogues between them; and

3. Specialized applications for disabled persons are often expensive, but no incentives exist to encourage companies or individuals to develop and/or transfer new and existing technologies and technology uses for that purpose.

Recommendations

Technology offers means to ameliorate the limitations posed by a variety of disabilities. Carefully guided action is required to ensure that appropriate devices and services are available to and accessible by Minnesotans with disabilities. The following recommendations provide the means to take such action and, given sufficient funding and staff support, could be implemented within a two- to three-year time period:

1. An ongoing Advisory Board on Technology for People with Disabilities should be established.

2. A mechanism should be established to gather information on existing technology for persons with disabilities and to dispense it through a central collection site.

3. A statewide media campaign should be developed to heighten public awareness of available technology-based products and services and their implications for persons with disabilities.

4. A sequential strategy should be developed to provide technology-related training to professionals in special education, rehabilitation, county case management, and other areas of caregiving, as well as to families.

5. Public agencies, private insurance carriers, and Health Maintenance Organizations should be required to expand their definitions of medical necessity, to revise their definitions of prevailing community standard, and to provide extended disability insurance coverage.

6. Medical Assistance should be revised so that it encourages, rather than prevents, technological advances.

7. The Medicaid Professional Services Advisory Committee should be expanded to include a subcommittee of persons familiar with new technological devices and services to advise the Department of Human Services on appropriate technology matters.

8. A matching grant program should be enacted by the Legislature to encourage the use of public and private sector funds to support new program alternatives that promote the use of technologies by people with disabilities.

9. Minnesota's Developmental Disabilities Council should study Pennsylvania's Assistive Device Loan Program and evaluate the advisability of proposing a similar program in Minnesota.

10. Grants, tax credits, and other incentives should be established and/or modified to encourage the development, modification, and transfer of technologies to meet the needs of disabled persons and to assist consumers paying for needed devices and services.

11. Assistance should be provided to companies to identify and document needs and existing technologies in order to help them design products usable by and accessible to people with disabilities.

12. A proposal should be developed for a Minnesota Center for Technology for Disabled People that would coordinate, support, and advance technology uses and applications for people with disabilities through implementation and training, information dissemination, technical services, research and development, and technology transfer.

Future Implications

Advanced technology is widely available in general, but its transfer to the special, long-term needs of persons with disabilities has been slow, sporadic and uneven. At the same time, the population of persons with disabilities is increasing. We are at a point where dramatically effective, practical applications could become reality and could be made widely available and accessible. The degree to which this will occur depends on the intensity and effective coordination of information dissemination, funding, and public and private sector research and development efforts.

We cannot afford to pass up the opportunity to utilize technology to its fullest potential in order to help people with disabilities fully participate in our society. Minnesota's economy has prospered from a strong base of technology-intensive firms, an enduring entrepreneurial spirit, a tradition of cooperation, and an abiding concern for our fellow citizens. These same strengths give us the ability to lead the nation in the application of new technologies to the needs of people with disabilities and to focus on the abilities, rather than the disabilities, of those with functional limitations.

The next five to ten years will be crucial to the shape of the future. Action must be taken in the areas of information sharing, funding, and research and development within a carefully conceived strategy that is fully supported with adequate human and financial resources; the costs of doing so will be far outweighed by savings in productivity, economic growth, and human dignity. We can afford to do no less.

Creation of an Advisory Council

Based on the recommendations of this task force, the Minnesota State Legislature appropriated funds for the public policy implementation and continued partnership through the Governor's Advisory Council on Technology for People with Disabilities (Executive Order 86-12), a program of the Office of Science and Technology located in the Department of Trade and Economic Development.

The experience of the Advisory Council can be replicated in other states through a coalition of consumers, producers, third party payors, service providers, education systems, library systems and representatives of state agencies that provide services for the disabled and the aging population.

Because providing technology for people with disabilities is a unique combination of products, services, funding, evaluation and training, expertise across a broad range of fields is required. The establishment of Minnesota's Council provides the necessary experience. Through this process each member has a particular expertise, yet they have an ability to focus on the needs of people with disabilities.

When discussing possible solutions, our Council has not lost sight of social, economic and political realities that exist for policymakers, business people, service providers and individuals with disabilities in today's world.

Often discussions expand to include practical problems such as: "We developed an apparatus for Bob so he can reach the top shelf from his wheelchair." "How do we market this to others?" or, "Mary just returned to work after her injury and here's how we've adapted her work station..." or "Paul can only use his index finger on one hand, but with the help of a microcomputer he's able to communicate with his family." The sharing of experience and personal commitment adds an important dimension to the Council's activities.

Minnesota's economy has prospered from a strong technology-intensive industry and an outstanding medical-and-rehabilitation community. The Council membership reflects those strengths. An important feature of the Federal-State Assistive Technology Bill is that it allows each state to capitalize on its own unique strengths in the creation of an interagency council and the designation of a lead agency.

Technology offers a means to compensate for limitations imposed by a variety of disabilities. It is a tool that can be used in all areas of life; in vocational, recreational and educational pursuits as well as in home activities at any point in a person's lifetime. As a tool involved in a variety of activities throughout a person's life, technology is different from most human service delivery systems. With technology there is no closure, no aging out, and no other defined endpoint; it is a continuous and rapidly changing process, one which requires a coordinated effort to ensure integration into existing systems. The advantage of this legislation is that each state will be able to develop a comprehensive, coordinated state policy by virtue of the key players that are members of Minnesota's Council. These same players have the authority to integrate appropriate technology devices and services into their own agencies' programs and businesses.

State efforts are necessary to ensure that funding mechanisms can respond to the need for technology. Many people with disabilities rely on Title XIX of the Social Security Act for assistance in obtaining medical and rehabilitation services. While there is national criteria regarding eligibility, states retain considerable discretion with regard to who is served, to the scope of service and to the duration of that service.

In Minnesota and other states, such discretion has prevented the acquisition of some significant categories of technology, such as augmentative communication devices. The rationale has been that such devices do not serve a medical need even though they serve a very real need for an individual who is speech impaired. The Office of Technology Assessment found that people with disabilities are often denied payment through current patterns of reimbursement because these programs were designed to provide assistance for acute medical problems rather than for the chronic problems faced by people with disabilities. "A significant effect of the current system is that, in the short term, funds may be saved while in the long term a greater amount of total funds is expended." (OTA 1982, p. 179).

Removing such obstacles to functional independence is a medical necessity. An important part of functional independence through the use of technology involves rehabilitation engineering services for conducting assessments needed to select equipment that is most appropriate for individuals and providing the training needed for safe and appropriate use of that equipment.

Often, an individual's needs require a variety of different technologies adapted to his/her unique needs. The skills of rehabilitation engineering are necessary to design an effective system; these services should be reimbursed in both public and private funding mechanisms.

In the area of funding, another crucial issue must be addressed: getting equipment to people with disabilities. As the previous discussion demonstrated, current funding mechanisms do not adequately address the need. Given the fiscal constraints facing most states and the high demand for limited private resources, a key component of any federal legislation will be a grant program that will ensure not only the planning for but the actual delivery of technologies for people with disabilities.

The success of such initiatives is measured by the availability and affordability of this technology to individuals. Success can also be measured by the degree of independence afforded an individual through the use of such technology. Lake Kissick is one such individual.

Lake is a person whose disabilities were so severe that his doctor told his family he would be a vegetable for the remainder of his life. Lake now lives in his own apartment using an electrical wheelchair and communication device. Lake works as a sales person for Prentke - Romich, the company that manufactures the communication device he uses (Kissick 1986).

Legislation that creates the incentive for states to gather a coalition of consumers, producers, advocates and professionals supplied with funding mechanisms that would be directed toward the acquisition of devices for individuals is an important step in helping states provide technology for people with disabilities.

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Senator **Harkin**. Brian McNulty, director of Special Education Services for Colorado Department of Education.

I will say to you as I said to everyone else, your statement will be in the record.

Dr. **McNulty**. I would like to first of all thank the committee and the staff for inviting me here today. I met with the subcommittee staff three or four weeks ago, and many of the issues that we brought up at that time have been addressed in the new versions of the bill and we are very pleased to see those.

I am here today representing the National Association of State Directors of Special Ed, and hopefully, speak for the rest of the State directors around the country in terms of their interest and concern in this area.

We feel that there is a real need in the field to move forward with technology. The bills, we think, are timely. We think they could be very effective in terms of the service delivery on children.

It is interesting probably for us to note that when we look at technology, that technology seems to be hitting us on all fronts, both in terms of instruction, in terms of management, and in terms of assistive devices.

And our perception again is that really, we cannot wait to integrate technology. Children's lives are at stake, and children are waiting, and their parents are waiting for us to integrate the technology and the advancements that are there.

When we look at areas like supported work; functional curriculums and serving kids out in the community to give them real life skills, these cannot just be words and phrases; they have to be real initiatives that reach the field as quickly as we can find out about them.

We do not want to see people waiting until they are 45 years of age until they get technology, whether it is instruction, or in terms of administration or in terms of assistive devices. So we have to move quickly.

In Colorado, we do have a statewide system that we started several years ago to look at developing service systems for augmentative and alternative communication devices.

And having gone around the State the last year to look at those kinds of systems and what's really happening out there for children, it's extremely exciting. We have a child over on our western slope who has cerebral palsy and is a very severely physically involved child that we got an augmentative alternative communication device to, she is now in regular first grade, and is communicating with her peers and her teachers very much like the technology you saw here this morning.

She is fully integrated into a regular first grade program. That kind of effect cannot be overestimated. She can talk to her peers. She can talk to her teachers.

We had another 18-year-old at the other end of the age spectrum who again was nonverbal, and we had been trying to find vocational placements for her, and had been very unsuccessful in finding placements.

We got a touch talker, and all of a sudden, again, by having a communication system, she all of a sudden was very easy to find placements for. Went into a real full-time job.

Those kinds of changes are things that we cannot afford to wait on. These people will miss their elementary school years, their secondary school years. They will miss vocational opportunities, I think, unless we act.

In terms of where the States are, we have met with about five or six representative States, but overall, I can tell you, the States sort of look like they did pre P.L. 94-142 when it comes to how even the service delivery system's out there. It is not very good.

While some States have been able to move ahead very quickly, some States are in the formative stages at best, and really are not prepared yet to provide services. And they really do not know what services are out there.

Really, what we are finding is, whose leading the initiative is parents. And again, I think you have heard some of that today. It is the parents who are having to take the initiative to go out and find systems, to train professionals, to get those systems integrated within the schools. And we do not feel that is really appropriate.

So you will find a great degree of unevenness around the country right now.

Since you have my written comments, I would like to really just quickly reference four recommendations.

The first one has to do with the need for systemwide development. One of the things that we know with our programs for disabled people right now is that it is an incredibly fragmented system of service delivery. You have to get a piece here and a piece over here, and if you are not the right disability, or your income level is too much, or if you're not the right age, then you don't fit in the system, and there is really not a human services delivery system. There is a system of fragmented services that, again, parents have to go around and broker themselves.

So we would encourage you to look at the bills that are saying, let's approach this from a systemwide basis. We feel that is very critical.

The second part of this recommendation though, is to maintain some flexibility within that system. Because once you give it to states, the uniqueness of each State is such that it really requires a great deal of flexibility.

We have changing consumer needs, and we have evolving technologies, so we cannot tie it down too tight or it is not going to work in terms of meeting the individual needs of families and systems that are out there.

I think also, there is a lot of talk about how much planning versus how much implementation. I would encourage us always to do both.

We need to get services out there now, and we need to continue to plan as we move along. But we cannot spend all of our time planning and thinking about things, and not getting actual services out to clients. I think we need to do both.

The final one around that service systems piece is, I think that we need to focus on outcomes. Again, I feel the evaluation system for this kind of a grant should be based on how well the States do, how many services did they provide you, what types of clients, and really make it sort of an outcome evaluation model.

And again, let the States then use their own uniqueness to describe what they have done and how they pulled the pieces together to work within their own State.

The second issue is one of funding. There is a great need for funding. These systems are expensive. All you have to do is look at the electric wheelchairs or the communication boards, and at $5,000, $10,000, $15,000 apiece, we find that we are strapped. We really do not have the fiscal resources to be able to meet the needs that are out there in the field.

Again, in Colorado this year, we estimate that we will reach 300 children. At best that is 30 percent of the population that is out there. We are not able to really meet the full need.

There is also, and I think you heard that from Marvin, the need for intensive ongoing training. We cannot just train one cadre of people. We have to be able to train parents. We have to be able to train people in the workplace. We have to be able to train teachers so that they know how to use the systems and they can be fully utilized.

So there has to be some kind of initiative that allows us to focus on training people who are going to interact with individuals who have assistive technologies.

I think also when we look at funding levels, we need to accept the fact that different States proceed at different levels, and that they're coming in at different levels, and that they are going to proceed at different rates.

So I think the funding strategy could allow that kind of a mixed funding approach that would allow different States to come in at higher or lower levels, depending on where they are in the planning and implementation process.

Finally, the one thing around funding that I think will have the biggest impact will be the definition. Who are we talking about? What do we mean by assistive technology? How broad based do we want that to be?

And that impacts, I think, on funding levels for you as well as for us.

The third issue is the issue of governance. We have recommended that this program go to the Governor's office. We think that to assume some accountability that it should go to the Governor's office.

But once it has gone to the Governor's office, to allow the States again to be unique in how they pull together their entities in terms of service delivery.

In Colorado, for instance, we have the head of rehab, the head of developmental disabilities, the head of special education, and the head of our DD council, came together to form an entity called the Rocky Mountain Resource and Training Institute that is working on supported work.

This unique combination was created to make it functional. And I think we could do something very similar with this bill. We will take the initiative to put together the prime players that need to be there to make this work.

I think the same issue also goes for even things like advisory council. One of the things you are going to hear from the States is, we have a State advisory council for special education. We have the developmental disabilities advisory council.

We have the governor's infant and toddlers' advisory council. We have the maternal child health advisory council. And the list goes on and on.

And it is getting so that we do not have time to do things because we are meeting all the time. And again, I am not sure always that advisory councils are the most effective way to get consumer input.

And I would say, let us look at least at allowing there to be some alternative strategies for how we might get consumer input, and that consumer input might be able to be more broad based than a council where you get single representatives on the council.

The last issue I would like to address is the role of the Federal Government. We think that probably the placement of this program in OSERS would make some sense to us, because it would address both special education and rehab services, two of the primary providers.

And certainly they have some good experience, I think, with the whole issue of looking at system change grants. So we think that makes some sense.

The second reason we think it makes sense is really because of the Part D personnel preparation program that comes out of OSERS right now. Again, as you heard already, there is a need for preservice training as well as in-service training.

The professionals who are coming out now, both teachers and support service staff, really are not trained to work with assistive devices at all, and we think there needs to be some tie-in to that Part D personnel prep training program.

The last thing I guess is that we see a primary role in terms of research and development, again, on the Federal level. While our States alone can do some things internally with our universities, and with the industries within our States, we really cannot muster the effect I think that comes from some nationally coordinated initiative to impact on industry and to look at research and development.

So we feel that there would be some type of a synergistic effect by having the 50 States really be able to work with the Federal Government in looking at what should be research initiatives, what should be leadership initiatives, and how could they work with industry.

So those are my four recommendations. I appreciate the opportunity.

[The prepared statement of Dr. McNulty follows:]

STATEMENT

OF

THE NATIONAL ASSOCIATION OF STATE DIRECTORS
OF SPECIAL EDUCATION, INC.

TO

THE SENATE SUBCOMMITTEE ON THE HANDICAPPED

WITH RESPECT TO

ASSISTIVE TECHNOLOGY

May 19, 1988

Mr. Chairman and Members of the Subcommittee:

My name is Dr. Brian McNulty. I am the Executive Director of Special Education with the Colorado Department of Education; a member of the Board of the National Association of State Directors of Special Education (NASDSE) and the chairman of NASDSE's Legislative Committee. I come to you today in that capacity. As an organization, NASDSE sincerely appreciates having the opportunity to present the views of state directors of special education regarding the need for federal leadership to increase and improve access on the part of disabled persons to adaptive and assistive technologies and services.

We wish to address four general topics:

1. the issue of governance of a state system of assistive technology service delivery,
2. how schools are using technology and how might they use technology;
3. barriers to meeting the technology-related needs of persons with disabilities, and
4. considerations, recommendations and solutions to these barriers.

Let me preface my statements by saying that we see a critical need for increased attention in the area of technology for individuals with disabilities. While assistive devices offer great promise to specific individuals, the field as a whole is ill equipped to meet this challenge. The development and availability of technological devices are sporadic at best and professionals who work with children and adults are not being adequately prepared to utilize what is available. In most States, these problems result in an uneven and fragmented delivery of services. Given these prefatory remarks let me now address the four general issues.

I. Governance Issue

In order to provide for adequate governance of a State system, there needs to be:

1. a single line of authority that can provide accountability to consumers, agencies and the federal government,
2. the coordination of services and clients across agencies,
3. a statewide system of information, referral and public awareness,
4. a coordinated system for state level planning, service delivery and evaluation;

Given these, we would recommend that you consider the following:

If a federally-sponsored assistive technology program is to address the needs of individuals from birth to death (which we support), it will require the coordination of services across a variety of agencies. In addition, any system which is developed will need to remain flexible enough to meet changing consumer needs and evolving technology. To achieve these ends we would recommend placing the program within the Governor's Office. Placement within this office could insure that interagency issues would be addressed and resolved in an effective and efficient manner. Since no single agency can address all agencies or disabilities, this appears to be the only viable option. Once placed within the Governor's Office, however, the statute should provide each state with maximum administrative flexibility as to how to implement the program. While the concept of a lead agency may be appropriate for Part H, technology imolementation requires a broader model of collaboration and service delivery. Other collaborative options need to be encouraged and explored within this program. Currently, numerous interagency collaboratives are in place in most states and there is no need to duplicate these initiatives. Within the state of Colorado, for example, the state directors of special education, rehabilitation, developmental disabilities, and the Developmental Disabilities Council already comprise a working board of directors (the Rocky Mountain Resource and Training Institute) that is implementing our statewide transition and supported work initiative. Such a collaboration may (with some modifications) prove to be a viable option for this program also. Clearly, a good Federal approach will allow the states to have flexibility in deciding how to organize for service delivery.

The point here is that successful implementation of technology legislation may necessitate the development of new organizational collaboratives within each state, and states should be allowed to and encouraged to develop their own unique and viable interagency approaches.

The second issue regarding governance has to do with how the State should consult with the interested parties (service delivery and users) concerning assistive technology. One approach has been the creation of advisory councils. There is an emerging concern within the states that only so much time is available to carry out implementation activities. Currently, within my own state, we already have a state advisory council for special education, a state developmental disabilities council, the Part H Governor's Council for Infants and Toddlers, the MCH Block Grant Advisory Council, to list just a few. When this list is added on to the already large list of working committees and organizations that also require active participation from agency directors, the prospect of yet another advisory group is concerning.

While the use of advisory councils may be an efficient strategy on paper, it seems that other approaches could be explored by individual states as part of the systems development process, and may provide us all with more effective and efficient ways to insure coordination and responsiveness. The main point is that there be consultation among the affected constituencies.

In other states, technology service systems for certain segments of the population with disabilities are already beginning, and might serve as the appropriate administrative focal point. For example, in the state of

Florida, a statewide technology resource program serving school age persons with disabilities resource program is already in place, operating through regional sites.

As an aside, given the rapidly changing nature of technology, it may not be effective to have single individuals appointed to a council for extended periods of time, but instead to develop a process which allows for broader input through different means. Given the need for private sector involvement, I'm not sure that their involvement on an advisory council would be seen as an effective utilization of their time or energies. As with the supported work initiatives, we may want instead to utilize their expertise as technical advisors, or on short term working groups, but not set unrealistic expectations for ongoing long term commitments on an advisory board.

My recommendation here is to provide states with the opportunity to be creative and let them exercise their leadership responsibilities while still addressing the outcomes that you feel are important. Increasingly, we seem to be legislatively and administratively misdirecting our energies towards the development and documentation of procedures rather than focusing on outcomes. I would encourage you, therefore, to define your outcomes, i.e., coordination and a responsiveness, and then let the states develop, implement and evaluate the methodologies and strategies for addressing these outcomes. In turn, the effectiveness of their strategies could be evaluated as a part of their systems development model.

II. How Are Schools Using Technology, and How Might They Use Technology?

The best analogy for describing where schools are now with technology is to compare them with where schools were in providing special education prior to P.L. 94-142. While some states and school districts have developed rather sophisticated systems of service delivery in this area, the majority of states and districts have not. Consequently, only a fraction of the students who could benefit from these advances in technology are fortunate enough to secure them. At best, services are sparse and uneven across the country. Even if a child is lucky enough to have the skilled professionals and technological equipment in one district, they will in all likelihood lose both if they move across district, county or state lines. And when expensive "high tech" equipment is involved, further problems arise over "ownership" when such moves do occur.

On the whole, professionals working in the field are not trained in areas such as augmentative communication, the development of individualized communication systems for students, or powered mobility. Since adaptive and assistive technologies and services needed to benefit from them are rarely, if ever, addressed in personnel preparation training programs, even recent graduates are unprepared to adequately address the technology needs of children.

Parents of students with disabilities, therefore, are often left to rely upon their own resources to identify and secure assistance and then find that they often must provide training themselves if they want the systems utilized within the school or community settings.

In areas where professionals and technology are available, however, the outcomes have been significant. The ability to participate and be integrated into the school and the community is significantly enhanced by technology.

The Communication System Evaluation Center in Orange County, Florida, is designed to meet the needs of nonspeaking and/or semi-intelligible speaking students, their families, and school personnel. Florida students between 3-21 years old and enrolled in public and private schools are eligible for pre-evaluation, evaluation, and follow-up services for the purposes of designing and/or recommending appropriate manual and/or electronic communication systems. This center also provides components and outreach team training. The inservice components address specific implementation issues and include vocabulary selection and display organization; communication interaction; facilitation of communication in the classroom; graphic representational systems; and role of occupational and physical therapists in augmentative communication. Team training focuses more specifically on evaluation, screening, and training issues for manual communication system users.

The effect of providing a child with a system to communicate with his peers, teachers and parents cannot be overstated. To emphasize this point, I'd like to use several examples of experiences that we have had in Colorado. For the past two years, the Colorado State Education Agency has been been working with local school district teams to provide training in the development of augmentative and alternative communication systems. While this year it is estimated that these teams will provide assessment to over three hundred students statewide, to date, due to limited resources, we are reaching less than a third of our districts. One only needs to hear about several examples, however, to comprehend the benefits of intervention in this area.

One 10 year old child with severe involvement and no speech had been assessed earlier and was believed to be functioning at a very low cognitive level. She was provided with a fairly sophisticated communication system that the team felt was appropriate, but would require a significant amount of time on the part of the child and the team to be fully utilized. To the amazement of the teacher and the team, this child mastered this system in less than 15 minutes and in a short period of time was communicating in full sentences.

Another younger child with cerebral palsy has been fully integrated into a regular first grade as a result of technology which allows her to communicate and participate in appropriate grade level activities. Another child born without arms mastered the use of a computer with a word processing system and types all of her assignments in and out of class using her toes on the keyboard. Finally, through the utilization of a "touch talker" we were able to find a real job for an 18 year old non-verbal student who before had no viable vocational placement alternatives.

While obviously cursory, these examples highlight what positive outcomes can and do occur when children and young adults have access to trained professionals and technological devices. Children whose participation before was constrained by their own physical limitations now have significantly increased access to the world around them. With the advances in technology, the limitations now reside not within the individual, but with the fiscal and human resources within our service delivery systems. Technology offers the promise of greater integration and development of a social network by providing physical and communicative access to thousands of individuals who would otherwise remain on the outside of society looking in.

III. What Are The Barriers?

While somewhat apparent from my earlier comments there are barriers which impede the delivery of assistive technology services to students with disabilities. While all too commonplace as a concern, the issue of funding continues to surface the primary concerns.

Not only are technology systems expensive to purchase and to adapt to individual's skills and needs, they also require upgrading as newer, more advanced models are developed and as the users needs and abilities change. Given the nature of the equipment, there is also the need to pay for warranties and maintenance contracts as typically these systems get rigorous usage. We have found that the assessment teams also need to have at their disposal a variety of devices and equipment for assessment purposes and to make appropriate recommendations for individual students.

We welcome an approach that would infuse new monies into the service delivery system--including the schools--so that we can better fulfill the special educational needs of students with disabilities by using assistive technology.

Several related concerns have to do with the question of fiscal responsibility and ownership. One relates to concerns that school districts have as to whether the provision of assistive technology services then makes it a related service under P.L. 94-142. Given the fact that P.L. 94-142 is only funded at 8% of the national average per pupil expenditure and not at the 40% level authorized under the statute, districts are naturally cautious about moving into new or broader areas of development which may have financial implications. Given that such services and equipment are not mandated services, districts find that they have been able to utilize third party payments such as insurance to assist in funding these devices. There is a concern that if this is included as a related service under the Act that third party sources of funding will diminish or disappear completely.

A legitimate role of the state governance unit would be to plan for the payment for assistive technology by the agencies in the service delivery system.

Related to this issue is the question of ownership. Who owns the equipment? Does it move with the child (even out of district and state)? Who is responsible for repairs? Does the equipment stay at school or may it be utilized 24 hours a day? If appropriate, can several children share in using the equipment, etc.? While appearing somewhat provincial, these are actually very difficult programmatic questions faced by districts when they purchase expensive equipment. These questions are exacerbated when you consider that often children outgrow (physically, mentally, and communicatively) certain devices and will need to be provided with more advanced equipment later on. Who should be responsible for the follow-up and tracking of both the equipment and the child's progress? If the child transfers to another district or transitions to the adult service delivery system, does the tracking and follow-along still occur and how? Who then becomes fiscally and programmatically responsible for replacing the equipment? While some of these issues are fiscal in nature others are system development issues which have not yet been fully addressed or resolved. Again, the state governance unit should plan for a system of case management or other follow-through and within system advocacy.

The second major barrier has to do with professional preparation, both preservice and inservice. Across the board, teachers and support staff have had little exposure or training in the assessment and utilization of adaptive or assistive technology. For many, their exposure to such advances has been limited to using a computer in class for computer assisted instruction. This lack of preservice training will continue to place both SEAs and LEAs in a catchup mode.

A major part of any technology initiative must also include an intensive inservice component. Our experience has taught us that the provision of ongoing intensive training is critical to the success of the program. Professionals need to be provided with "hands-on experience" with systems to experience both their capabilities and limitations, and so that they can appropriately match the skills of students with the available technology. In addition to learning themselves, these professionals must also be able to provide training and information to the student, parents, teachers and peers. All of this requires a significant investment of time and resources on the part of both the SEA and LEAs. Concurrent with any major new national initiative on technology, there will need to be a similar priority and funds directed to the EHA, Part D personnel preparation program.

Another concern has to do with paperwork and legal considerations. If there has been one common concern regarding P.L. 94-142 it has had to do with the amount of paperwork and consequent overemphasis on procedure rather than an emphasis on quality outcomes. To this end I would ask that the committee give careful consideration to not requiring yet another set of individual plans and legal procedures. We are already required to have IEPs, IHPs, IWRPs, and IFSPs. It is sufficient to say that the need for any assistive technology should be specifically addressed as a component of the child's IEP. Thus, the procedural safeguards of the EHA necessarily would be available to the parents and the schools.

IV. Considerations and Recommendations

1. Our first recommendation has to do with the need for systems development. The current service delivery system is segmented and fragmented by age, disabilities, severity levels, income levels, etc. Any future national developments should set as their primary goal the integration of these disparate pieces. Given the difficulty of accessing the current system it is essential that we work toward the development of an integrated system of service delivery across agencies.

Therefore, it is our recommendation that the focus of any bill be patterned after the other system change/development grants. These initiatives, while posing numerous challenges to agency participants have also offered new opportunities to plan and work across traditional agency boundaries in developing, implementing and evaluating services on a systems level. This approach should not require a great deal of prescriptive language, but rather should focus on the desired outcomes, and what might be the minimum components of such a system. In

Colorado, we have been extremely successful in integrating children into regular public schools and adults into real work using the system's development model. By allowing us to develop our own strategies, we have been more effective than we would have been had we been required to follow a prescribed plan. Initial and continued participation in the program could be based on how effective each state has been in developing and implementing its plan and ultimately on outcomes such as how many and how well have individuals with disabilities been served. The most recent proposals provide essentially that needed balance.

2. The second recommendation addresses the utilization of funding. As with the first recommendation, consideration needs to be given to provide maximum flexibility to address the varied levels of sophistication of different states. While some states have well established systems for at least portions of the population, other states have yet to undertake any systematic initiative. Most if not all states will require additional planning if the bill addresses persons birth to death. Consideration will also need to be given to allow states to participate at different levels of the planning process and to proceed at different rates.

As a part of the interagency planning process questions regarding interagency tracking of equipment and services referral systems, resource sharing, etc., will in all likelihood need to be explored and funded at some level through the state grant program. Clearly, however, the major fiscal issues will revolve around the need for intensive inservice training and the purchase and maintenance of equipment. Services such as case management, follow-up services to schools, agencies and families, and program evaluation are examples of other services that should be considered appropriate expenditures.

3. While already mentioned, the third issue relates to governance. It is our belief that if any program is to successfully address the needs of individuals from birth to death then it should be administered through the Governor's office or by the Governor's designee. Having been so placed, however, each state should be free to develop its own unique interagency collaborative arrangements to address the needs of the state. States should also be allowed to develop their own system for representational involvement from a variety of consumers, agencies and the private sector. While an advisory board may be one acceptable alternative, other methodologies for involvement may prove to be even more effective at soliciting broader involvement.

4. We recommend that continued participation in this program be based on an evaluation of outcomes where the criteria are increased numbers of people served appropriately.

5. Finally, we would like to make some recommendations regarding the role of the federal government as it relates to this program. From our perspective it would make most sense to assign the administration of this program to OSERS. Placing the program here should result in at least two of the primary players on the state level being involved (special

education and vocational rehabilitation). In addition OSERS has had experience in administering several systems-change grant programs, including the new Part H program.

Placing the program in OSERS may also assist in addressing the concern regarding pre-service training. If there is to be a major national initiative, some attention needs to be focused on providing leadership to professionals at both the pre-service and inservice levels. Either as a direct part of this program or under the Part D, EHA, personnel preparation program OSERS should be given responsibility to address this need. However it is addressed, OSERS is the appropriate entity to administer this priority.

Lastly, there is a need for federal involvement in the area of research and development. While individual states can do some work within their own states with industry and universities, they cannot have the effect that the federal government has. It seems that it may be appropriate to have a mechanism whereby the participating states can work with the federal government in identifying priorities and issues for research and development. The synergistic effect of having the states working together in this initiative could be more significant than having 50 separate projects. For this reason there is both a coordination and leadership role for the federal government within this program and especially within the area of research and development.

I appreciate the opportunity to come before you today and hope that you will find our comments useful in your efforts to provide assistive technology to individuals with disabilities. We feel assured that with the continued partnership between the states and the federal government we will continue to make significant progress for persons with disabilities.

Thank you.

Senator HARKIN. Very good testimony. Thank you very much, Mr. McNulty.

And next, Peter Howell, Director of Program Evaluation at the South Carolina Vocational Rehabilitation Department. Again, your testimony will be made a part of the record.

Mr. HOWELL. Thank you, Senator.

On behalf of Mr. Dusenbury, I would like to thank you, the committee, and the staff for allowing us the opportunity to provide input into this vital area.

Mr. Dusenbury apologizes for his unavoidable absence today and asks that I deliver his testimony, which I will do in an amended fashion, given the time limitations.

I am commenting as a representative of the South Carolina Vocational Rehabilitation Department, which delivers assistive technology services under the Rehabilitation Engineering provisions of the Vocational Rehabilitation Act, to persons with disabilities, who are preparing for work.

As such, I have seen many vivid examples of the benefits of applications of assistive technology in opening employment and independence doors for persons with severe disabilities, who would have otherwise been denied.

Assistive technology, in conjunction with other rehabilitation services, can enhance, and certainly hasten, productive vocational outcomes, and can do much to lessen the cost and dependence aspects of severe disability.

Mr. Dusenbury's comments on the issues surrounding assistive technology come from our service experiences. These experiences have led us in South Carolina to strongly believe that the delivery of assistive technology services should be tied to discernible outcomes.

The provision of these services should have as its main goal the promotion of independence, the improvement in functioning, and gainful productivity.

As such, we believe that any legislation which seeks to expand and promote assistive technology should direct efforts toward populations who can most benefit, such as children, to enable them to benefit more significantly from academic and other vocational preparation training experiences; and also to adults as they seek to gain employment and greater independence.

The key to effective assistive technology services, from our perspective, is the delivery of such by personnel who have the expertise, the sensitivity for a person's limitations, and the informed and updated knowledge base to effectively marshal available and adaptive technology toward practical solutions of limitation deficits.

I will defer here, because there has been considerable mention made of the need for both formal academic training and in-service training to prepare these personnel, and we also echo those sentiments.

I mentioned that to be effective, assistive technology must be delivered in as practical a fashion as possible. Let me illustrate.

In South Carolina, before we developed the expertise in the specifications for vehicle modifications, we relied totally on outside vendors of such technology to set specifications to meet particular client needs, and then to deliver this service.

Once we gained the expertise and begin setting the technology specifications ourselves to meet the clients' needs, which were then adhered to by outside vendors; we found that the cost of these services dramatically declined, while at the same time, the utility of this technology application for clients increased, as did their satisfaction level with this application.

When the subject of assistive technology is raised, many people become frightened by visions of robotics, computer gadgetry, and other extremely sophisticated and expensive Star Wars type innovations.

While these connotations can form part of the picture, we and our colleagues in vocational rehabilitation engineering in the Southeast have found that the vast majority of assistive technology innovations can be considered in the low technology category.

Many of the most useful assistive devices which can be creatively, inexpensively, and very effectively adapted and modified by rehabilitation engineering personnel are of the common commercial variety. I will not elaborate on the long list of examples of such at this time, but they are contained in Mr. Dusenbury's written testimony.

The marketplace appears to be receptive to technological advances, but without the expertise of assistive technology personnel and programs, we have found that vendors can tend to adapt the client's needs to their existing technology, rather than adapting, modifying, or otherwise providing innovation to their technology to best meet the needs of the client.

We feel that the marketplace wants to participate in any expansion and enhancement of assistive technologies, but they must be invited and then directed.

In reviewing the latest draft of the proposed legislation, I was particularly gratified to note the continued inclusion of Title III, which deals with specific strategies to decrease the funding mazes and increase funding opportunities and incentives.

I feel that no matter how sophisticated and comprehensive assistive technology networks become, without attempts to correct the crucial regulatory and other disincentives such as product liability, lack of private sector research initiatives, and the lack of creative funding options, this legislative initiative would not have full, lasting, and meaningful impact.

The authors of this section of the legislation are to be applauded for their foresight and innovation.

On the subject of the mechanism by which the intent of the proposed legislation would be administered within the States, I feel that for the sake of continuity, uniformity, and flexibility, that legislation should designate a lead agency.

It would appear appropriate that in the selection of a lead agency, the criteria of a centralized statewide presence with interagency ties, and a demonstrated expertise in the delivery of assistive technology services, should be the benchmarks.

It is our perspective that the most appropriate lead agency, given these criteria, would be vocational rehabilitation.

I realize that in some states the governor may feel the vocational rehabilitation agency may not be capable of the necessary service delivery, promotion, and coordination efforts necessary to realize the full intent of this legislation.

However, on the whole, Vocational Rehabilitation agencies are seen as the primary service provider for the largest percentage of the population with severe physical disabilities. Rehabilitation agencies by virture of their legislation and practices have formed significant linkages with other applicable public and private service delivery programs, and they have unquestionably developed significant expertise and experience in the delivery of assistive technology services through Rehabilitation Engineering.

It should be noted again that any consideration of the designation of the lead agency should place prime emphasis on the statewide presence of that agency and on that agency's ability through its structure and legislative mandate to provide consistent direction and control over its local sub-divisions so there can be uniformity and continuity in service delivery and the liaisons necessary for effective service linkages and coverage.

Also, contained within the testimony is a description of our current efforts with the Rehabilitation Engineering Center Grant that we have been awarded by NIDRR to disseminate rehabilitation technology information, in cooperation with the University of Virginia Rehabilitation Engineering Center; United Cerebral Palsy Research Foundation/Wichita State University; and also, with Louisiana Tech. University. Prior to the awarding of this grant, there were no federally funded Rehabilitation Engineering Centers located in the region of approximately 38 million people, and we found that much of the valuable research which had been carried out was sitting on shelves and not being utilized.

We have been overwhelmed, quite frankly, with the response that we have received from this grant effort.

In conclusion, we would like to say that there was considerable skepticism on the part of some as to whether there would be cooperation by the existing rehabilitation engineering centers in any kind of outside dissemination.

Also, quite frankly, there also appeared to be considerable skepticism regarding Vocational Rehabilitation's ability to deliver assistive technology services.

Let us say emphatically that instead of there having been reluctance, there has been overwhelming encouragement and support, which makes us think that our project, the rehab engineering provisions, of vocational rehabilitation legislation, and any further development of legislation in assistive technology, are extremely welcomed and timely.

We feel that the rehabilitation engineering centers, which already exist, will overwhelmingly support these efforts and initiatives.

Thank you very much on behalf of Mr. Dusenbury.

[The prepared statement of Mr. Howell, representing Mr. Dusenbury, follows:]

TESTIMONY
before
SENATE SUB-COMMITTEE ON THE HANDICAPPED
on
# THE SUBJECT OF ASSISTIVE TECHNOLOGY
for
PERSONS WITH DISABILITIES
by
Joe S. Dusenbury, Commissioner
SOUTH CAROLINA VOCATIONAL REHABILITATION DEPARTMENT

I would like to take this opportunity to sincerely thank you for allowing me to provide testimony on the subject of assistive technology and its benefits to persons with disabilities. I am commenting as a representative of the South Carolina Vocational Rehabilitation Department which delivers assistive technology services under the Rehabilitation Engineering provisions of the Vocational Rehabilitation Act to persons with disabilities who are preparing for work. As such, I have seen many vivid examples of benefits of applications of assistive technology in opening employment and independence doors for persons with severe disabilities who would have otherwise been denied. Assistive technology in conjunction with other rehabilitation services can enhance and certainly hasten productive vocational outcomes and can do much to lessen the cost and dependence aspects of severe disability.

My comments on the issues surrounding assistive technology come from our service experiences. These experiences have led us in South Carolina to strongly believe that the delivery of assistive technology services should be tied to discernible outcomes. The provision of these services should have as its main goal the promotion of independence, improvement in functioning, and gainful productivity. As such, I believe that any legislation which seeks to expand and promote assistive technology should direct efforts toward populations who can most benefit, such as children to enable them to benefit more significantly from academic and other vocational preparation training experiences, and to adults as they seek to gain employment and greater independence.

Maintenance of present physical condition and functioning level, reduction of physical suffering and/or the prolongation of life without hope of recovery are laudible aims for medical technological advances, but I feel that the promotion of these directions should be left for other legislative considerations.

The key to effective assistive technology services from our perspective is the delivery of such by personnel who have the expertise, the sensitivity for persons' limitations, and the informed and updated knowledge base to effectively marshall available and adapted technology toward practical solutions of limitation deficits. To this end, we and our colleagues in Rehabilitation Engineering Programs in the Southeast feel that legislation promoting and expanding the scope of assistive technology should seek to provide opportunities and incentives for the formal educational preparation and continuing in-service training of such personnel, and provide for the vital linkage mechanisms necessary to broadly share, in an ongoing and comprehensive fashion, information on state of the art technology, and more importantly, innovative applications of such.

I mentioned that to be effective assistive technology must be delivered in as practical a fashion as possible. Let me illustrate. In South Carolina, before we developed the expertise in the specifications for vehicle modifications, we relied totally on outside vendors of such technology to set specifications to meet particular client's needs and to deliver this service. Once we gained the expertise and began setting technology specifications to meet the client's needs which were then adhered to by outside vendors, we found that the cost of these services dramatically declined, while at the same time the utility of this technology application for clients increased, as well as their satisfaction with this application.

When the subject of assistive technology is raised, many people become frightened by visions of robotics, computer gadgetry, and other extremely sophisticated and expensive "Star Wars" type innovations. While these connotations can form a part of the picture, we and our colleagues in Vocational Rehabilitation Engineering in the Southeast have found that the vast majority of assistive technology innovations can be considered in the low technology category. Many of the most useful assistive devices, which have been creatively, inexpensively and very effectively adapted or modified by Rehabilitation Engineering personnel, are of the common commercial variety. A common gauge whose numbers are enlarged, a school desk to which hinges and swivels are added for height and angle adjustment, a light sensor modified to give an audible signal when light is detected, a straight metal splint which is curved in such a way as to increase the grasping function, and a series of color coded lights to signal the sequence in which control buttons on a machine should be pushed are but a few examples of the creative low technology applications which form the foundation of an effective assistive technology program.

The marketplace appears to be receptive to technological advances, but without the expertise of the assistive technology personnel and programs, we have found that vendors will tend to adapt the client's needs to their existing technology rather than adapting, modifying or otherwise providing innovation to their technology to best meet the needs of the client. We feel that the marketplace wants to participate in any expansion and enhancement of assistive technologies, but they must be invited and then directed.

In reviewing the latest draft of the proposed legislation, I was particularly gratified to note the continued inclusion of Title III dealing with strategies to decrease the funding mazes and increase funding opportunities and incentives. I feel that no matter how sophisticated and comprehensive assistive technology networks become, without attempts to correct the crucial regulatory and other disincentives such as product liability, lack of private sector research incentives, and lack of creative funding options, this legislative initiative would not have full, lasting, and meaningful impact. The authors of this section of the legislation are, in my opinion, to be applauded for their foresight and innovative, suggested approaches to these potential barriers.

On the subject of mechanism by which the intent of the proposed legislation would be administered within the states, I feel that for the sake of continuity, uniformity, and flexibility that the legislation should designate a lead agency. It would appear appropriate that in the selection of a lead agency the criteria of a centralized statewide presence with interagency ties and a demonstrated expertise in the delivery of assistive technology services should be the benchmarks. It is our perspective that the most appropriate lead agency given these criteria would be Vocational Rehabilitation. I realize that in some states the Governor may feel the Vocational Rehabilitation agency may not be capable of the necessary service delivery, promotion, and coordination efforts necessary to realize the full intent of this legislation. However, on the whole, Vocational Rehabilitation agencies are seen as the primary service provider for the largest percentage of the population with severe physical disabilities. Rehabilitation agencies by virture of their legislation and practices have formed significant linkages with other applicable public and private service delivery programs, and they have unquestionably developed significant expertise and experience in the delivery of assistive technology services through Rehabilitation Engineering.

It should be noted again that any consideration of the designation of the lead agency should place prime emphasis on the statewide presence of that agency and on that agency's ability through its structure and legislative mandate to provide consistent direction and control over its local sub-divisions so there can be uniformity and continuity in service delivery and the liaisons necessary for effective service linkages and coverage.

By way of conclusion, I would like to briefly describe a program that we have developed in South Carolina that I feel particularly relates to the intent of this proposed legislation. The South Carolina Vocational Rehabilitation Department in October, 1987, was awarded a five year Rehabilitation Engineering Center grant from the National Institute on Disability and Rehabilitation Research for the purpose of disseminating research on the state of the art of assistive technology to practitioners such as Vocational Rehabilitation counselors, occupational therapists, physical therapists and others closely aligned with the rehabilitation movement in the Southeast region. Prior to the awarding of this grant, there were no federally funded Rehabilitation Engineering Centers located in the region of approximately 38 million people, and we found that much of the valuable research which had been carried out was sitting on shelves and not being utilized. We saw the need, with the support of the Rehabilitation Engineering Centers located at the University of Virginia, the Cerebral Palsy Research Foundation/Wichita State University, and Louisian Tech University, to disseminate this information to those who could put it to best practice. The three areas in which the South Carolina Vocational Rehabilitation Department Rehabilitation Engineering center will concentrate on adaptive seating in collaboration with the University of Virginia, job adaptation in cooperation with the Cerebral Palsy Research Foundation/Wichita State University, and vehicle modification and driver training in cooperation with Louisiana Tech University. Although we are not quite a year old in this effort, we have been truly overwhelmed with the response from the rehabilitation community in their desire for this information. Equally rewarding has been the interest on the part of the cooperating Rehabilitation Engineering Centers in their desire to see that this information reaches those who would most benefit.

As to the question of how the federal government can help in this effort, I see a need, based on the outstanding cooperation already received, to enhance linkages and expand upon the networks that already exist to provide the broadest and most effective dissemination of this state of the art information.

I again want to thank this committee for the opportunity to provide input into this vital area and we on the service delivery level greatly look forward to the expansion and enhancement initiatives proposed by this pending legislation.

In conclusion, I would like to say that there was skepticism on the part of some as to whether there would be complete cooperation from the existing Rehabilitation Engineering Centers with our efforts to expand the dissemination of technology through the grant I have previously described. There also appeared to be considerable skepticism regarding Vocational Rehabilitation's ability to deliver assistive technology services.

Let me emphasize that instead of there being reluctance, we have received overwhelming encouragement which makes me believe that our project and the legislation which mandates the use of rehabilitation technology was extremely welcomed and timely. We certainly feel that we can count on the Rehabilitation Engineering Centers to overwhelmingly support these efforts.

Senator HARKIN. Thank you very much.

One or two questions for each of you. Dr. Fifield, you stressed the need for personnel preparation programs. Should personnel preparation initiatives be left to the Federal Government operating out of OSERS, or should the States be required to do personnel preparation activities also?

In our legislation, we are considering both approaches. Does one have any particular advantage over the other?

Mr. FIFIELD. I am not sure we would want to change the system as is, the Federal Government primarily provides stimulus and focus.

What I think we need is that stimulus. Eventually training needs to be picked up by the State in our systems of higher education.

What I'm recommending is that initially there be stimulus grants like we have in special education, and in the health fields, where there are major critical shortages of personnel.

Eventually, this is a training responsibility that should be built into training programs at the preservice level. Curriculum offerings should be added.

Senator HARKIN. In your testimony you did not indicate a need to train users' families. Is there such a need? And who should respond to it? The Federal Government? The State?

Mr. FIFIELD. That certainly is an omission. In training the consumer, I would definitely include the family, particularly a family with children, where the initial training provided to the child is by the family. Training is needed as much for the family and the significant others in the lives of the handicapped individual as the persons themselves.

Senator HARKIN. Thank you.

Mr. McNulty, we have heard that resource centers are useful and a model for Federal aid to the States.

Is it also important to let the States be flexible in their service delivery approaches? Should we select only the center-based approach?

Mr. MCNULTY. I would certainly say no. Again, one of the things that we have looked at is a training model that really allows us to work with the local resources that are there.

And again, the center concept in a State like ours, where we have hundreds of thousands of square miles of service delivery, would not prove real effective.

Instead, what we have found out is, we have to take our resources out to the local areas, train staff, use resources that are there. That is one approach. But I would not limit the approach to only a center approach, because you need to involve the training of staff, adapting of materials that are locally available.

So I would say you would need to at least include both.

Senator HARKIN. You have had an opportunity to review our May 6th draft of specifications of a bill. What is your overall reactions to the draft, and will it do a good job of helping the States?

Mr. MCNULTY. Overall, the May 6th draft I think is a significant improvement. As a matter of fact, we felt that it integrated almost every concern that we had addressed previously to this.

It does say that the States will develop a plan, but it provides them some flexibility in terms of a bunch of other issues around implementation.

It provides some outcome measures. It says what should be in a plan. But again, in terms of the use of funds, it says, here are some things you can do with funds, but it does not say that you must go through every step.

So we felt it was really a significant improvement. The only issue I guess we would still look at is that issue of definition. And that I think is a question that you have to ask, is how broad is the definition going to be because we felt if we make it to cover the waterfront of every assistive device, including self-help devices, for instance, it becomes broader and broader, and we dissipate then potentially how many clients we have reached.

Senator **Harkin**. Rachel, have you seen our May 6th draft?

Ms. **Wobschall**. Yes.

Senator **Harkin**. Do you have any thoughts on the approach we take?

Ms. **Wobschall**. I think one real advantage is that it allows each State the opportunity to decide what system is best for them.

In Minnesota we have a very close partnership with our technology-intensive industries. And we found that that is very helpful in terms of development efforts.

So I would say that that is a real critical part.

Senator **Harkin**. What about you, Mr. Howell, have you had a chance to see the draft yet or not?

Mr. **Howell**. Yes, sir, we have.

Senator **Harkin**. Any thoughts on this aspect of it?

Mr. **Howell**. Yes, sir, we very much like the flexibility involved there also. In our testimony comments, regarding the designation of a lead agency, we endorse rehabilitation. But the real issue is not the designation of rehabilitation over anybody else, but the designation of an appropriate lead agency.

We feel some legislative guidance to the States in the form of selection criteria would be very helpful in ensuring that at the local level, where the services are delivered, there in fact be control for continuity and responsibility. We feel that this could be done without really impairing the States' flexibility or their discretion.

Senator **Harkin**. Dr. Fifield, same question of you: Have you seen the draft, and how do you feel about that approach?

Mr. **Fifield**. Yes, I have, Senator. I would echo the comments that have been made here. I would add one point that is the practicality of it. When we talk about costs, the feasibility of such legislation is questioned.

That has to be considered. That is the only caution I would put in it. Definition is primarily the main factor here, because if it is too broad, it is too costly. Maybe we need to start small and develop.

Senator **Harkin**. Mr. Howell, you made a pitch for the Vocational Rehabilitation being the lead agency. But would you also feel that each State ought to decide—perhaps let the governor's office decide? How do you feel about that?

Mr. HOWELL. Yes, sir, as I mentioned, we obviously strongly feel that vocational rehabilitation, for the points we have mentioned, would be appropriate.

But more importantly, there should be some designated entity; so the important thing is to have selection criteria that will ensure effectiveness. That could mean the placement in some other agency, but this should be done with some criteria that would allow some consistency at the service delivery level.

Senator HARKIN. Mr. McNulty, we are considering two approaches to helping the States. One would provide money to all of the States on a noncompetitive basis. The other would provide funds only to a limited number of States on a competitive basis.

Which approach do you think is better?

Mr. McNULTY. I guess it depends on what you want for your outcome, but I would have real concerns about making it a competitive program. The reason being, unless the long term strategy again is to eventually fold in all the States.

What you find then is the large States who have the population centers also seem to have the grant writers, and seem to get more than their fair share of the resources.

The States who have less State staff, and sophistication in grant writing, do not seem to usually get to participate. And we have seen that happen under the Part D Personnel preparation program, and that was one of our concerns initially.

I think what it also does is that it brings in the States who, because in their application, look, and probably are, more sophisticated and further along, it brings them even further along, then, from the States who are maybe not as sophisticated and do not have as many programs in place.

So in effect, you widen the gap, then, between States who are involved in services now and States who aren't, and it becomes harder then for those States to catch up.

So we would think a noncompetitive program that again has certain criteria or components in it, and a certain outcome evaluation would prove more effective to bring along the entire country.

Senator HARKIN. Mr. Howell?

Mr. HOWELL. We agree, very much so. You do not want to create a situation where you have "haves" and "have nots". In a competitive grant situation, those States that would most likely apply, and most likely be awarded, would be the States that are further developed, therefore, creating a broader gap as has been said.

So we agree on the noncompetitive also.

Senator HARKIN. Ms. Wobschall?

Ms. WOBSCHALL. I would also agree with that, that we need an effort for all States. And I would really encourage as much as possible, in the development of outcomes, that those funds be directed specifically to acquiring technology for individuals with disabilities.

In Minnesota, for example, I am the only staff person. And because of the visibility that our governor has given this project, it has really served to integrate and foster the use of technology in all of the agencies.

We have representatives from voc rehab, from education, from the private sector. And what it has done is allowed given visibility to using technology within those systems.

And so I would really see—and what we are finding is that we need the money specifically for getting technology for individuals.

Senator **Harkin**. Dr. Fifield?

Mr. **Fifield**. My comments differ a little bit. It depends on how much money we have, whether we use it for stimulation or distribute it equitably to everyone.

If stimulation and programs of excellence are needed, possibly a competitive approach, has value, rather than distributing it out equally, we may realize more benefit for the investment.

It is also important to determine what funds we are referring to. Are we talking about distributing training monies, research and development monies, direct service monies or monies to purchase assistive devices? Stimulation would work well for training not so well for direct service.

Research and development could be put into programs of excellence in some center-based type program.

And so I think there are a number of other variables that need to be considered when we are talking about distributional funds.

Senator **Harkin**. Thank you. I guess that is the question I have. Obviously, we are not going to have a lot of money.

I am wondering if, again, it is best to take what limited money we have and to dribble it out bit by bit? Or would we be better off targeting it on a competitive basis to stimulate certain programs and States, get them going, and then move on to other States.

In other words, rather than putting it all out there where everybody gets a little bit but can't do much, perhaps it would be better to focus it on a few areas where some States are coming up with creative ways of joining with the private sector or getting resources out or whatever it might be, and really getting those up and running, and then moving on to some other States.

So while I agree with you on the competitive versus the noncompetitive, Mr. McNulty and Mr. Howell, I come from a small State that often gets left out on these grants, too.

But when you are dealing with a small amount of money, sometimes we may have to come up with a creative approach that tends to focus that money.

I do not know. I have not decided. I ask you the question honestly to try to get some of your best thinking on that.

If you have any further observations on that, I would appreciate it either now or perhaps you could submit it in writing to us.

Mr. **McNulty**. One other point is, I would guess that not all States are prepared to commit at this point in time. And especially when you are looking at a systemswide development model, that in a lot of the States this is not an emerging issue yet, and they are not ready to participate; they are very caught up in P.L. 99-457 infant preschool initiative, and do not feel that they can—so my guess is you will get a staggered entrance somewhat, anyway; that if you were to offer it to the majority of States, that they would not all participate at this point in time.

Senator **Harkin**. That might be true.

Ms. **Wobschall**. One of the points I have with regard to that is, as we develop the infant-toddler program, and other programs, we begin to integrate technology in those systems from the beginning.

So to the extent that is possible, I would encourage looking at supplying funding for those kinds of things.

In my dealings with the traditional funding systems, and getting them to accept new technologies, augmentative communication devices for example the thing that I keep hearing from both the public and private pairs are, we do not see it in practice; we do not see it in the community; we cannot pay for it until we know of its efficacy in terms of a device or service.

Senator **Harkin**. Okay. We are going to have to bring this hearing to a close. I would announce again to everyone here that we have an ongoing demonstration all day today until 5:30 in 216 Hart Building, the next building over, with a lot of assistive technology devices.

That will be all for the remainder of today. Tomorrow morning we will reassemble here at 9:30 for our second day of hearings.

[Whereupon, at 12:24 p.m., the subcommittee adjourned.]

ASSISTIVE TECHNOLOGY FOR PERSONS WITH DISABILITIES

FRIDAY, MAY 20, 1988

U.S. SENATE,
SUBCOMMITTEE ON THE HANDICAPPED,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The subcommittee met, pursuant to notice, at 9:35 a.m., in room SD-430, Dirksen Senate Office Building, Senator Tom Harkin (chairman of the subcommittee) presiding.

Present: Senators Harkin, Simon, and Weicker.

Senator HARKIN. The subcommittee will come to order.

I have been told that at 11:30, we have five roll-call votes, so we have to finish by 11:30. In the interest of time, I will just ask that my opening statement be made a part of the record.

[The opening statement of Senator Tom Harkin follows:]

OPENING STATEMENT OF SENATOR HARKIN

Senator HARKIN. Yesterday, people with disabilities spoke from their hearts and to our hearts. They told us inspiring stories—about how they had the character and the technology that, together, helped them overcome the effects of their disabilities. We cannot help but remember Teddy Pendergrass' statement to his physicians, that, when he was discharged from the hospital, he planned to keep on making music.

Also yesterday we learned that there are many unmet needs calling for a prompt Federal response. Brian McNulty captured the essence of the testimony when he said that people whose participation had been constrained by their own physical limitations now have significantly increased access to the world around them. He added, "with the advances in technology, the limitations now reside not within the individual but with the fiscal and human resources within our service delivery systems."

Today, we will continue to hear from people with disabilities. Denny Theesfield, of Armstrong, IA, was disabled in Vietnam. But he and his friends used technology to put him back to work and literally to save his family farm. Denny will speak to our hearts, but he also will instruct our minds.

So too will other witnesses. They will tell about the major functions of life—learning and work—that can be opened more fully to people with disabilities when assistive technology is available. They will repeat the message that we heard so clearly yesterday—that there is a great need to ensure that users and professionals alike receive on-going training to use assistive technology. And they also will tell us about the programmatic and fiscal barriers facing Federal and State governments and the private sector.

I would ask, Senator Simon, if you have any opening comments.

OPENING STATEMENT OF SENATOR PAUL SIMON

Senator **Simon**. Just briefly. I regret that I couldn't be here yesterday. I chaired a hearing on the South African situation, and I'm going to have to leave here early.

I simply wanted to commend you, Mr. Chairman, and everyone here who is involved in this kind of activity. I am particularly pleased that you have the Executive Director of the Lekotek Center from Illinois here as one of your witnesses. As you will hear, it is the kind of program that we have to be moving on.

I stopped by the technology exhibition in the Hart Office Building yesterday to see what's being done with technology for children with handicaps so that they can function better. I got in a wheelchair that had a device so that you can stand up, even though you're in a wheelchair. But it will cost, apparently, about $8,000 or $9,000 for that wheelchair. How do we make sure that technology is available?

I would also like to commend companies like IBM who are moving in this field. I don't know whether they're going to make any money out of this or not, frankly. I hope they do. But whether they make any money or not, they're helping this country in a very significant way.

There's just no question—we can do much better in this area of technology—and I say that as one who is wearing two hearing aids. I can assure you, we have to improve that technology. We're a still a long way from where we ought to be in terms of what hearing aids ought to be in our society.

Again, Mr. Chairman, I commend you for this hearing, and I commend all those who are here who have been leading to improve the quality of life for all Americans.

Thank you, Mr. Chairman.

Senator **Harkin**. Senator Simon, thank you very much for those very poignant and, I think, on-the-mark statements.

I also want to put Senator Weicker's statement in the record at this point.

[The opening statement of Senator Weicker follows:]

OPENING STATEMENT OF SENATOR LOWELL P. WEICKER, JR.

Senator **Weicker**. Mr. Chairman, I want to commend you for convening two days of hearings to examine ways to promote the use of assistive technology for persons with disabilities.

Most of us take for granted the technological advances that enrich our daily lives—from televisions to computers. For individuals with disabilities, the promise of technology can literally mean the difference between a life of dependence and isolation and a productive life in the mainstream of society. Assistive technology has proven its value in assisting disabled individuals to become independent and contributing members of our workforce. Through rehabilitation engineering, worksites can be modified to permit disabled individuals to obtain jobs that previously would not have been available. Through applied technology in the classroom, disabled children can be integrated into the educational system with their nonhandicapped peers.

In the course of these hearings, we will examine what impediments exist to the widespread use of assistive technology, such as the lack of coordinated, state-wide service delivery systems, and the need for funding and additional research and development. We will also receive recommendations as to what the Federal Government can do to reduce those barriers.

Technology can open the door of opportunity for persons with disabilities. Sophisticated assistive devices such as electronic communication devices enable individuals who cannot speak to express themselves, and environmental control devices permit persons with limited functional abilities to operate telephones and to direct the use of a pencil or utensil. These are just a few examples of the exciting developments resulting from assistive device technology. As a result of these advances, disabled individuals are becoming increasingly integrated into our educational system and the workforce.

Legislation being drafted by the subcommittee chairman, which I support, calls for a comprehensive approach that would allow States to develop the capacity to provide technology and related assistance, create a national information and referral network, and promote applied research, development and training. Such a coordinated approach will ensure that existing technology and future advances will be available to all people with disabilities—not just a privileged and determined few.

I also want to commend Senator Kerry for his leadership in introducing legislation to create "assistive device resource centers" for disabled children, and I look forward to working with him, Senator Harkin and members of the Subcommittee on the Handicapped as we proceed with comprehensive assistive technology legislation.

Senator **HARKIN**. Our first panel will address how assistive technology can enhance functioning in different areas.

Our first witness, is Sally DeVincentis, Director of the National Lekotek Center, who will discuss the role of assistive technology in early education and the role of parents. Dr. Herb Rieth, Chair of the Special Education Department at Peabody College of Vanderbilt University will discuss the role of assistive technology in enhancing learning in special education.

I am particularly proud to introduce Denny Theesfield who is a farmer from Armstrong, Iowa. After Denny became disabled in Vietnam, he thought that he would have to stop farming. But with the aid of assistive technology, he has been able to continue in his proud family tradition of farming. He will present testimony on the role of assistive technology in enhancing employment opportunities.

Finally, we will hear from Tom O'Bryant, Director of Equal Opportunity Affairs, with the Champion International Corporation, and a member of the President's Committee on Employment of the Handicapped. Mr. O'Bryant will also address the role of assistive technology in enhancing employment opportunities.

Our first witness will be Sally DeVincentis, Executive Director of the National Lekotek Center in Evanston, Illinois. We welcome you to the subcommittee. For you and all the other witnesses who are here, your statements will be made a part of the record in their entirety.

Again, we are really on a strict 2-hour limit today so I would ask you to try to sum up your testimony in 5 minutes.

Sally, welcome.

STATEMENTS OF SALLY DeVINCENTIS, EXECUTIVE DIRECTOR, NATIONAL LEKOTEK CENTER, EVANSTON, IL; HERBERT RIETH, CHAIR, SPECIAL EDUCATION DEPARTMENT, PEABODY COLLEGE, VANDERBILT UNIVERSITY, NASHVILLE, TN; DENNY THEESFIELD, ARMSTRONG, IA; AND TOM O'BRYANT, DIRECTOR, EQUAL OPPORTUNITY AFFAIRS, CHAMPION INTERNATIONAL CORP., STAMFORD, CT

Ms. DeVincentis. It's really a great privilege to be here.

I thought perhaps I should start by defining exactly what that word "Lekotek" means. It's a Swedish word, which makes it a little difficult in this country. Lekoteks were started in Sweden by parents of children who were severely physically and mentally impaired.

Essentially, what Lekoteks are, they are resource centers for families. The original purpose was to have families care for their children in the homes, so lending of products is very important.

The mission of Lekoteks is the integration of all people with special needs into the mainstream of society, a very Swedish concept which is also very important here.

I was one of a group of parents and professionals who first brought the Lekotek to this country. That was in 1980. Today there are 45 sites, and there are 19 in Illinois, and there is also one in Iowa.

Four years ago, the National Lekotek Center developed a computer project. We did that because so many of our children were unable to talk, walk or even hold a pencil. We felt that, really, the way out for these children was to develop products and technology that could help them function in the real world.

We call that division of Lekotek Innotek, which is short for Innovations and Technology. Mary Trichman, who is with me, is the Director of Innotek, so I would like to introduce her.

Today, there are many Lekoteks with an Innotek program which provides technology to families. I would like to address two needs that we have clearly found in delivering services to children that we hope that this particular legislation will address.

The first one is that children have very specific and special needs in technology which is not always similar to adults. The second, a major problem that we have found is that very often technology exists, but we're not able to get it out to people who need the most. So distribution is a major problem for technology.

I would like to talk a little bit about why technology for children is a little bit different than adults. Our particular interest is in adaptive computers, and I will really speak to that particular subject.

It's easy to see how computers are very important to adults, and very often vocational opportunities have pushed forward development of computer technology. So if you're an adult and you can use a computer, you can always get a job as a computer programmer or someone who can do word processing, and it is a terrific advantage, vocational advantage, for an adult.

But somehow these innovations for adults have very slowly trickled down to children. I think part of that is that children have very different needs, and they're not necessarily vocational needs. I would like to give you an example by telling you a story of something a mother recently told me.

This mother had a child who was severely affected with cerebral palsy, and the child was a very floppy child, could not hold up its head, could not talk, could not walk. So from the time the child was very young, the mother would pick up the child, put the child over her shoulder and prop its head on her shoulder and would go places.

So about the age of four they got an electric wheelchair for this child and they put the child in the wheelchair, and they made rather a remarkable discovery—that the child's whole idea of mobility was what he could see over his mother's shoulder, and he had no idea about what going forward meant, and he had no idea about planning where he was going to go. So you can imagine, this idea of adaptive technology for this child required a whole new cogitative development because his idea of mobility was so different than everybody else.

The point of this story is that children who have not had normal experiences in childhood often grow up with a very distorted view of the world. That's why at Innotek, we are really very excited about some of the opportunities that technology offers to our children. Truly, a lot of the hardware is there. What we see is missing is really some of the software that revolutionizes children's way of thinking.

Our children need experiences that simulate normal childhood experiences, and we think it can be done in adaptive computers. We're not talking about software that is on the market now that sort of color matches and electronic ditto sheets. We're talking about a real revolution in software; software that really simulates experiences of normal childhood development.

I think a lot of that thought process exists in universities, but it sure doesn't exist in the retail stores. You can sell and buy it. The question is, how long do our children have to wait for that? It could make all the difference in the world to their developing intelligence.

When we ask the question, "When is this going to happen?" the things that we think about first are: How do you pay for such development? We know that software development is enormously expensive. The second is, after you have it, how do you distribute it to the people who need it the most?

At Innotek, our greatest challenge has really been how do you pay for services. Our family simply just can't afford it. Many of our families are young families because they have young children and they have, really, overwhelming needs and overwhelming costs. Just the simple idea of thinking about a family who has to purchase diapers for the next 12 years, that's just a very tiny, but very major expense to a family. Certainly, affording computer hardware and software is very expensive, and out of the reach of most families.

Our families need help from private industry, they need help from the Government, and they certainly need help figuring out how to creatively finance these products. I would like to comment that the new revisions on this legislation address some of those that I think could be developed very well and as opposed to the first piece.

As for the challenge of distribution, I would strongly recommend that the committee consider a national network of assistive technology centers. I envision a center very similar to the way that major corporations work very successfully. Do it in hierarchial states, starting from the top. I would say have several national centers that really look at this whole field conceptually, that they are your research and development centers that lead people into the future and have a vision.

The second stage would be that each state have a distribution center, just the way Sears does it. That is a much more practical way——

Senator HARKIN. I am going to have to interrupt because of the time. Could you just summarize your remarks please?

Ms. DEVINCENTIS. The last is really that each community have their own outlets that address the community needs very specifically. That's really it.

My last word would be to perhaps make the goal of the Assistive Technology Bill the same as Lekotek's Innotek which is to make computers available—just about as available as toasters and TV's.

Thank you.

[The prepared statement of Ms. DeVincentis follows:]

lekotek.

national lekotek center
2100 ridge avenue, evanston, illinois 60204 (312) 328-0001

Remarks to: The Senate Sub-Committee on the Handicapped, Chaired by Senator Tom Harkin

From: Sally deVincentis, Executive Director, National Lekotek Center, 2100 Ridge Avenue, Evanston, Illinois.

Subject: Comments on the proposed Federal-State Assistive Technology Bill.

Date: May 8, 1988

My name is Sally deVincentis. I am the Executive Director of the National Lekotek Center. Since Lekotek is a Swedish word, let me take just a minute to explain what it means.

Lekoteks are resource centers for families, whose children have special needs. Although the first Lekotek was begun in Sweden, sites are now located throughout the world. The mission of Lekoteks is to ensure the integration of all people into the mainstream of life. They do this by providing families with whatever they need to care for their children in the home.

I was one of a group of parents and professionals, who helped begin the first Lekotek in the USA in 1980. There are now 45 sites in 19 of your states.

Four years ago the National Lekotek Center developed a computer project. We did this because many of our children were so physically impaired they could not talk, hold a pencil, or use their hands to sign. These children were fully aware of the world passing in front of them, yet they had no way to communicate or participate. Technology offered a way out of their broken bodies.

Because of this need Lekotek created a technology division called INNOTEK. In the last four years lekoteks all over the country have begun similar INNOTEK services, motivated by the great need of our children and the truly crusader spirit of parents.

Providing support and self-help resources for the special child and family

My remarks today are based on INNOTEK's experience over the last four years. I will address two immediate and practical issues:

1. The unique needs of children regarding technology

2. The challenge of technology distribution to families with handicapped children.

Disabled children's need for technology is quite unique and different from those of an adult. Let me explain.

Much adaptive technology has been developed to meet the needs of adults. This is particularly true of computer technology. It is easy to see how an adult, who is physically disabled, can get a job if he is a computer programmer or does word processing. Vocational opportunities have greatly motivated such technology advances.

These results, however, have only recently filtered down to children.

It is time to think of the very unique needs of children.

Let me give you an example. A mother recently told me this story. Her child, who has cerebral palsy, could not walk or talk, because his muscles are so floppy. Ever since he was born she would lift him up, prop his head on her shoulder and carry him everywhere. At four, when he got his electric wheel chair, his mother made quite a discovery. She found that all these years his idea of mobility was what he could see while looking over her shoulder. He had no idea of what it meant to look where you were going. Whenever he got somewhere it was surprise to him how it happened. Before he could use his wheel chair a lot of retraining had to take place.

The point of my story is that children who have not had the normal experiences of childhood can have very distorted views of the world. This is why at INNOTEK we are enormous excited about the future of technology. We know that children as young as two, despite the severity of their disability, can access computer technology. The hardware is there. What's missing is a revolutionary look at software.

Our children need software that simulates normal childhood experiences. Not electronic ditto sheets, but creative programs that mirror the normal cognitive development of a child. Such software exists in university labs across the country, but you can't find it on the shelves of any retail stores. There is no question that such software can be produced, but when is the critical question for our children.

The question of when is bound by two challenges:

1. How do you pay the cost of such technological advances?...and
2. How do you distribute technology to the people who need it the most?

At INNOTEK cost has been our greatest obstacle to providing these invaluable services to children. For many of our families just keeping their child alive takes every bit of their resources. They simply can not afford the expense of technology. Our families need help.

Help from private industry.
Help from government .
Help from those who understand creative financing.

As for the challenge of distribution I strongly recommend the Committee consider a national network of Assistive Technology Centers. I envision a system similar to those successfully used by major manufacturers to distribute their products. Do it in three hierarchial stages. Starting from the top:

1. Several national centers designated as research and development sites for new products and concepts.
2. Each state have a major distribution center that makes available equipment, information and training.
3. Community based technological centers that are consumer oriented and responsive to local and regional needs.

If General Electric can successfully distribute refrigerators using such methods, certainly the US Government can do it.

In closing let me share with you the goal of INNOTEK and that is ...To make adaptive computer technology as ubiquitous as TV's, telephones and toasters.

Why not make that the goal of this Assistive Technology Bill!

Senator HARKIN. Thank you very much, Sally.

Next is Herb Rieth, the Chair of the Special Education Department at Vanderbilt University in Nashville; also President, I understand, of the Technology and Media Division for the Council for Exceptional Children.

Welcome to the subcommittee. Please proceed.

Dr. RIETH. Thank you very much, Mr. Chairman, for the opportunity to testify. As you mentioned, I am testifying on behalf of the Council for Exceptional Children and the Technology and Media Division of the Council for Exceptional Children.

The Council for Exceptional Children consists of persons involved with and concerned about the education of exceptional individuals, and the Technology and Media Division involves persons interested in using technology to improve teaching, research, and development applications for persons with handicaps.

In the testimony, we will focus on the educational applications of technology. It will be divided into two sections. The first deals with the issue of technology as a tool for learning; and the second will address some of the key points in the legislation.

As far as a tool for learning, the technology has been proven to be very effective and very powerful. We are finding that students are able to learn more rapidly and remember information for longer periods of time. They're able to apply the information across different skill areas, and different environments.

The whole concept of learning is changing. Whereas currently many people conceive it as a static concept, relegated to the schools, we are talking more about the concept of learning as a lifelong endeavor. With the transformation from an industrial, information-based society; there is more emphasis on the need for continuous learning, and we support this concept of learning.

Currently technology is serving as an enabling and empowering tool for individuals who have difficulty learning. They are able to acquire information that they may not have been able to learn before, or learn it more readily. It is applicable across a large age range, span. We find evidence, at a preschool level, that technology (computers) can help youngsters discriminate shapes, forms, learn language skills, explore their environment; all very important for subsequent learning.

In school, technology is a tool that can assist youngsters learn to read. They can learn vocabulary words more rapidly and can read more rapidly. We are making some breakthroughs in the area of reading comprehension, understanding what people are able to read and then apply the information to other areas.

In the area of mathematics, students who have difficulties—seniors in high school who had difficulty doing basic addition, subtraction facts, are now able to learn this information more rapidly. They are able to apply it to different problem situations that one encounters in everyday life.

In the area of spelling; linking computers to VOTRAX or DECTALK or speech devices enables youngsters to learn more rapidly and apply the information to some other forms of communication. Word processing, an important communication skill, will enable youngsters to communicate with teachers, peers, and other people in their environment.

We are also finding that there is increased research and development in the area of problem-solving, enabling people to understand logic, reconciling disparate statements thereby empowering them to learn additional pieces of information.

As we move to adults, many of the principles that we talked about before apply. Many of the principles of learning that would apply for youngsters in school situations apply to people who are stroke or accident victims. We also find that the technology can enable some handicapped individuals, particularly those with learning disabilities, severe emotional disturbance, are able to learn vocational skills.

They are able, in many cases, to learn personal interaction skills, using video disks and other devices to acquire these important skills, to make them employable and to enable them to retain employment.

Technology opens up access. Technology enables some youngsters, through wheelchairs, to go to school whereas before they hadn't been able to do this. Or, for other youngsters, the technology, through telecommunication systems, local area networks, enables them to acquire information, to communicate with other people. So this ends up being an important enabling skill.

It enables people to have greater access and control over their environment: controlling temperature, access to information, through television, and VCR's communication through word processing systems and other speech synthesis devices. Vocational environments where there are opportunities for persons to have robotic work stations, become accessible. Persons also have access to learning systems that enable them to acquire employment; enables them to broaden their knowledge as the job situation changes.

Does that give me a quick summary of legislative points?

Senator **Harkin**. Just sum it up; go ahead.

Dr. **Rieth**. The legislative points we want to submit for your consideration, one is the use of the term "technology assistance" as a focus; that is using technology to assist persons, in providing learning, vocational and leisure opportunities. The focus should be on the individual applications. Whereas we have standards for hardware and software, we can't lose track of the individual, with their idiosyncratic needs for technology.

Again, we emphasize the need for research and development. We need to develop with additional hardware and software applications. We need to develop new technologies as our sophistication increases; also focusing on the issues of training, which other people have addressed, model programs, and the participation of the persons with handicaps in leadership and decision-making roles as we deal with technology assistance.

Thank you.

[The prepared statement of Dr. Rieth follows:]

STATEMENT OF

THE COUNCIL FOR EXCEPTIONAL CHILDREN

and

THE TECHNOLOGY AND MEDIA DIVISION

to

THE SUBCOMMITTEE ON THE HANDICAPPED

of the

U.S. SENATE

with respect to

ASSISTIVE TECHNOLOGY FOR PEOPLE WITH DISABILITIES

MAY 20, 1988

Presented by:

Dr. Herbert Rieth
President
The Technology and Media Division

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Mr. Chairman:

I am Dr. Herbert Rieth, Professor and Chair of the Department of Special Education at Vanderbilt University in Nashville, Tennessee. My following statement is presented on behalf of The Council for Exceptional Children (CEC) and its Technology and Media Division (TAM), of which I am President.

As you know, CEC is the international association of professionals and others involved in and concerned about the education of students with handicaps as well as students who are gifted and talented. TAM is an organization of CEC members devoted to the improvement of research, development, training, and demonstration activities related to the application of technology to exceptional individuals.

We believe that technology can be a powerful tool for improving the quality of life for all people, but most especially those with handicaps. We commend Congress for recognizing the importance of technology over the years. One hundred nine years ago, Congress authorized the establishment of the American Printing House for the Blind, which has been devoted to bringing the technology of the day to sightless persons throughout the nation.

Over the years, efforts of the Library of Congress, the Department of Education in rehabilitation and education, the Veteran's Administration and others have played a major role in advancing technology applications. We particularly want to commend the Congress for the new legislative authority created in 1986, Part G of P.L. 99-457, and we hope that with some modest funding, better educational technology can be developed and made available.

Today, we come before you to suggest that it is time to take a major step forward. The age of electronic technology has created an opportunity to dramatically improve the lives of persons with handicaps of all ages. We believe that our society cannot afford to miss the opportunity to assure that such persons have access to appropriate technology assistance. We recognize that at this hearing testimony will be given on a wide range of issues. We have been asked to focus our comments on educational applications; we will do so, but we want to convey our support for the comprehensive view as legislation is developed. Our testimony will address two major issues. First, we will present ways technology assistance can significantly improve educational opportunities for persons with handicaps. In this regard, we strongly believe that education is a lifelong process and that while our examples will focus on children and youth, application should address persons of all ages. Second, we will propose basic principles that any legislation developed should address.

USING TECHNOLOGY TO IMPROVE EDUCATIONAL OPPORTUNITIES FOR PERSONS WITH HANDICAPS

Improved educational opportunities have accrued for persons with handicaps through the application of technology to improve their ability to: a) learn, b) actively participate in an education environment, and c) apply newly learned information across environments.

a) Technology As a Learning Tool

As a tool to improve the learning of persons with handicaps, technology is an exciting and inescapable feature of modern life. It is becoming a more accessible and integral part of teaching handicapped persons. According to Budoff, Thormann, and Gras (1984), the advantages of using technology to teach persons with handicaps include:

1) Individualization and self-pacing: With well-programmed Computer Assisted Instruction (CAI), students work at their own pace with material that meets their specific needs. In addition, rate of presentation and response may be regulated for each student.

2) Immediate feedback: Students receive immediate feedback about their performance.

3) Consistent correction procedures: Students with handicaps are often confused by corrections that are too wordy. CAI can provide specific, consistent correction of errors.

4) Repetition without pressure: Since the computer is emotionless and infinitely patient, repetitive tasks may not be aversive or embarrassing for the student, but indicative of mastery. This is particularly important for slow-learning students who do not experience success in academic tasks frequently or easily.

5) Immediate reinforcement for correct responses: The software provides immediate positive reinforcement for correct answers, which motivates students.

6) Well-sequenced instruction: A task may be analyzed, broken down into manageable steps, and then programmed. Special education teachers often do not have the training or time to construct the consistent, well-sequenced instruction that most handicapped students need, and that good software can provide.

7) **High frequency of student response:** If the interactive features of the computer are put to full use, students get more practice solving problems than they do working in large groups or with work sheets.

8) Repeated demonstration of mastery of academic subject matter: A sense of mastery of subject matter, especially academic subject matter, is very important to students who have experienced and continue to experience failure in instruction. The computer allows them to review their earlier attainments and recall them. The students can demonstrate to themselves and others their competence in academic subjects. These ego boosts can be critical at times of frustration. The special education student can be "in control of" his learning.

9) Motivation: This can be described at two levels. Many students with handicaps are excited by working on a computer, even doing class work. For others, it is an excellent motivator to allow time for computer games as a reward for work completed. Earning computer time may result in more focused and concentrated work by easily frustrated students who produce slowly or not at all in their usual assignments.

10) Minimize disabilities: The computer enables the poor or inefficient learner to minimize or circumvent significant barriers to learning. Students who are able to understand basic math concepts but unable to do error-free calculations (due to poor memory, visual, perceptual, or other problems) can manipulate numbers and letters with greater ease and accuracy in an interactive mode. Their reasoning abilities can be expressed without interference from their problems in producing output. Using the computer as a work processor may help a special education student bypass writing, spelling, and language arts problems by allowing the student to edit and revise work easily. The time and energy formerly spent on laborious rewriting of rough drafts can be spent developing ideas in a legible and acceptable form. The ready availability of spelling or punctuation checking programs can pit the child against himself. The computer motivates him to reduce spelling or other writing errors, since he can chart his errors after each attempt to reduce them. Most important, the child unable to produce acceptable work can demonstrate his productivity to himself and others.

A substantial amount of information is available documenting the positive effects of technology on the learning of persons with handicaps (Behrmann, 1984; Budoff, Thorman, & Gras, 1984; Cain & Taber, 1988; Carmen & Kosberg, 1982, Cartwright & Hall, 1974; Goldenberg, 1979; Hartley, 1977; Hasselbring, 1982; Haus, 1983;

Jamison, Suppes, & Wells, 1974; Kulik, Bangert, & Williams, 1983; Rieth & Polsgrove, 1983). In addition to the professional literature, there are personal vignettes I would like to share that poignantly illustrate the power of technology to improve the learning, self concept and motivation of persons with handicaps.

- I can vividly recall a group of high school students with mental retardation enrolled in an inner city high school in Indianapolis, Indiana who, despite being classified as 10th, 11th and 12th graders, had achievement levels between 2nd and 3rd grade level. Most of the students had long histories of school failure despite their assignment to special education programs. Many attended school only about 50% of the time. Early in September, my colleagues and I introduced a modified learning and instructional program that included computer-based instruction to assist students in learning basic math facts, basic reading skills and spelling skills. We also used computer games to motivate students to accurately complete paper and pencil assignments. Within one month, all the students were attending school every day and were not cutting classes. Within two months, the students were submitting all assignments on time and were not failing any subjects. By the end of the year, the students had increased their achievement in math and reading an average of 2.5 grade levels and none of the students dropped out. Students who remained in the program for a second year also increased their achievement an additional 2.5 grade levels. Thus, in two years, the students had tripled their rates of achievement due to excellent teaching, good instructional and behavioral management strategies, and the use of computers.

- In another study, my colleagues and I worked with 20 high school students with handicaps who were unable to learn basic addition, subtraction, multiplication, and division facts. Many of these students had been working on the same facts since third grade. By this time, they had resigned themselves to failure and showed very little interest in continuing to work on this material. The average student completed about 20 math problems every half-hour. Once computer-based math drill and practice began, the students increased their work speed to an average of 10 problems correct per minute. After four weeks of starting computer-based instruction, the students standardized math achievement test scores increased an average of two full grade levels.

- Recently, we were working with a group of 40 junior high school students with learning disabilities from the Metropolitan Nashville, Tennessee Schools who had great difficulty learning basic math operations. Computers were used to teach the students and computer games were made accessible based on meeting negotiated performance criteria. Tommy, one of our star pupils, was making rapid progress. He was elated with his progress and when asked what he liked best about working with the computer, he responded with a wide grin and said, "it makes me feel like a genius".

These vignettes highlight the power of technology to transform the lives of persons with handicaps. In addition, there is substantial research to support the impact of technology on the learning of students with handicaps. In this next section, we will briefly review information highlighting the effectiveness of technology to enable students with handicaps to increase their rate of learning.

Knowledge Base

Microcomputers have been used in special education for the past nine years and research indicates that the number of computers being placed in special education classes is rapidly increasing (Becker, 1986; Cosden & Semmel, 1987). By far, the most common use of the microcomputer in special education is to develop proficiency in the basic academic skills of math, reading, spelling, and writing(Becker, 1986; Cosden & Semmel, 1987; Okolo, Rieth, & Bahr, in press; Rieth, Bahr, Polsgrove, Okolo, & Eckert, 1987; Russell, 1986). Experts, such as Lesgold (1983) and Torgesen (1984), believe that drill and practice is required to enable children with handicaps to attain fluency in basic academic skills. They argue that special education students do poorly in reading and math because they may have failed to master basic skills. Making these basic skills fluent and automatic requires extensive practice for which the microcomputer is ideally suited.

Math

For years, educators have argued that, in order to fluently recall math facts, students must be provided with many opportunities to practice these facts. More recently, the computer has emerged as one way of providing students with large amounts of extended practice (Gagne, 1983). Virtually all of the studies investigating the efficacy of math drill and practice software have found that fluency has increased on the problems that the students practiced. Trifiletti, Frith, and Armstrong (1984) analyzed the effects of math drill plus tutoring on a group of handicapped students' proficiency with unknown math facts. They found that 40 minutes of computerized tutoring plus drill per day was more than twice as effective as an equivalent amount of teacher delivered math instruction. Hasselbring, Goin, and Bransford (1987) examined the effect of tutoring plus drill on the math performance of a group of 150 learning disabled students. They reported that after only 49 days of instruction on math software, a computer instruction group increased the number of facts recalled by 73% over their pretest score. During the same period, a non-computer contrast group showed no change on the number of facts that they could recall from memory. Kelly, Carnine, Gersten, and Grossen (1986) examined the efficacy of using a videodisc to teach fractions to a group of high school students with mild handicaps. They concluded that the videodisc was an effective teaching tool that can be used to demonstrate concepts clearly and is substantially less labor intensive than teacher-based instruction.

Reading

There is growing consensus that the primary reading difficulty experienced by students with mild handicaps is at the word, rather than the text level of processing. Thus, students with mild handicaps require instruction designed to increase fluent and efficient word recognition. Jones and Torgesen (1987) found that computer-based instruction enabled students to increase their reading speed by 26% versus a 4% increase for students taught by teacher-based instruction. The computer-based instructional group increased their accuracy by 20% while the teacher-based instructional group demonstrated only a 5% increase. Johnson, Carnine, and Gersten (1986) reported that computer-based instruction was an effective method of efficiently and effectively teaching reading vocabulary. Jones, Torgesen, and Sexton (1987) used a computer-based reading program for 15 minutes per day over a ten week period to teach a group of handicapped students reading skills. They found that it resulted in a 27% increase in reading speed. More impressively, the students receiving the computer practice showed a simultaneous 20% increase in accuracy on a generalized word list that was never practiced during the training. Roth and Beck (1984) examined the effect of computer-based practice on reading decoding and found that students using computers increased their reading speed by 17% while a contrast group who did not receive computer instruction produced only a 3% increase in their reading speed. Similarly, Spring and Erry (in press) reported that well designed computer-based training of reading decoding skills increased the fluency of students with mild handicaps.

Spelling

Teague, Wilson, and Teague (1984) worked with a group of young students with mild handicaps to compare the efficacy of computer-based spelling instruction with traditional spelling instruction. The results indicated that the students made significantly more improvement when computer-based instruction was used. In a series of studies, Hasselbring (1982, 1984) reported that "voice presentation" of words via computer in combination with imitation plus modeling feedback was successful in developing high levels of spelling accuracy by such students. It was also found that this approach was significantly better than traditional spelling instruction. Rieth, Bahr, McCarthy, & Polsgrove (in preparation) used a computer linked DEC TALK coupled with a distributed practice study procedure to increase the weekly spelling test scores attained by a group of 15 students with handicaps by 40% over pretest scores.

Writing

Morocco and Neuman (1987) conducted a two year observation study investigating the use of word processors to teach writing to learners with mild handicaps. They concluded that procedural writing instruction coupled with computer instruction was the most successful technique for teaching writing to these learners.

Ellis (1986) compared student writing under three conditions: (a) handwriting, (b) word processor, and (c) word processor plus idea processor (outlining program). Following strategy training, the students' writing improved under all three conditions with the word processor showing the best results.

Problem Solving

Maddux (1984), Schiffman, Tobin, and Buchanan (1982), Russell (1986) have suggested that the computer is a powerful tool for the development of thinking and problem solving in students with learning disabilities. Probably the most publicized way of developing problem solving skills has been through the use of interactive programming languages, the most prominent being LOGO. Turkel and Podell (1984) used LOGO Turtle Graphics to teach thinking and problem-solving to eight students with mild handicaps. Students employed mathematical concepts such as estimation of distances, angles, plotting points on a grid, spatial awareness, and sequencing. Also, students had to find and correct errors in programs. They found that the students were generally focused, systematic in their problem-solving behavior, organized, on-task, logical, and they appeared motivated. Woodward, Carnine, and Collins (1986) used simulations to teach health-related problem-solving skills. They reported that the simulation group was superior to the conventional group on measures of problem solving in the areas of diagnosing health problems, prioritizing them regarding their effects on a person's longevity, and prescribing appropriate remedies. Collins, Carnine and Gersten (1987) reported good success in using computer-based instruction to teach high school students with handicaps to draw conclusions from two statements of evidence and to determine whether a two statement argument was logical. Despite the evidence that technology is effective in assisting these students to learn, there is additional research and development that must be done to increase our knowledge of how to most effectively use this powerful tool. Simultaneously, we must strive to develop new and more sophisticated applications to assist persons with handicaps. In the following section, I will briefly highlight some of the more pressing needs for additional research and development.

Research and Development Needs

Despite the ready availability and the efficacy of computers as teaching and learning tools, many teachers are not using computers to teach students with handicaps (Rieth et al., 1987). Research must investigate factors such as the lack of educationally sound software, logistical problems in scheduling microcomputer use, and the lack of teacher training and support that contribute to the limited use. We must conduct additional research to determine the conditions which facilitate the widespread adoption and diffusion of technology among special educators. Teachers still primarily use computers for math, reading, spelling, and writing instruction. Therefore, further studies are needed to identify additional applications in these areas as well as the areas of science and social studies. We need to know more about the instructional features of software that will influence student learning. Given the finite resources available to purchase additional machines, we must learn whether students can be grouped for computer-based instruction, how the groups should be composed and how student performance while working in groups should be evaluated. In the area of problem solving we have just begun to develop a knowledge base that will guide important research.

b) Technology to Improve Functioning in Educational Environments

Technology is also a tool that can be used to make the learning environment more accessible and enhance individual productivity. Computer technology as a tool for children to access educational environments can be divided into four general categories; 1) a learning (academic) tool, 2) a living tool, 3) a vocational tool, and 4) a recreational tool.

The Computer as a Learning (Academic) Tool

As described earlier, computers are powerful instructional tools. To use the tools, one must be able to access the environment. For example, technology can facilitate access. Students with handicaps can use telecommunications to access essential learning information. Wheelchairs are now equipped with microprocessors enabling handicapped persons greater access to schools.

Communication devices enable students, heretofore unable to communicate in school, to interact with teachers and their peers. Spoken text allows individuals with visual handicaps or those with severe reading deficits to use word processing.

The Computer as a Living Tool

Computers can facilitate daily living activities in a broad array of environments. For children with multiple handicaps, the computer can be used to manipulate the environment by controlling tape recorders, electrical appliances and robots capable of manipulating food and drink. Voice synthesizers and communication software packages allow non-verbal children to talk to teachers and peers. Children with visual impairments can read written material with optical scanners and synthesizers as well as access electronic media such as electronic encyclopedias. Children with handicaps can interact with other children using telecommunications. Word processing, spread sheets, and database productivity tools can assist in communication, solving math problems, learning to balance a checkbook and home living skills (e.g. retrieving recipes).

The Computer as a Vocational Tool

Computers are being used extensively in schools to prepare students for future vocational settings. Our society is changing from an industrial base to an information base. Cottage industries specializing in information manipulation are increasing in number and the manufacturing industry is rapidly developing a technological base. Technology allows persons with handicaps to participate in this transformation.

Just as technology can be adapted to allow most students to use a word processor to satisfy academic and communication needs in school, it can also be adapted to access to learning vocational applications. Technology manufacturers such as Apple and IBM include design parameters in new equipment that ensure that individuals with a disability can utilize standardized interfaces. Robotic workstations have been developed at such companies as Boeing Industries to enable quadriplegic employees to continue with their jobs. For individuals who are difficult to integrate into the work setting, telecommunication offers an option of working at home or in a smaller cottage industry better suited to meet the needs of individuals with a disability. Services such as mailing lists, data bases, etc. can be maintained by children and youth who have the capability of learning the skills necessary to be productive yet need special medical or other assistance.

Computers as Recreation and Leisure Tools

Play, recreation, and leisure are important parts of the learning process and technology can provide more normalized access to these activities. For example, socialization is enhanced through telecommunications. Auto dialers can easily contact friends and augmentative communication devices can support direct one to one interactions. Graphics packages for drawing and color printers to make hard copy allow access to art. This software can be accessed using adapted devices allowing a child who cannot hold a crayon or a child with limited cognitive ability or perceptual motor dysfunctions to express themselves by drawing. Synthesizers can enable a child unable to use a piano keyboard to compose music and explore music and sound. Popular video games such as "Super Mario Brothers" and "Pac Man" become accessible with adapted devices and electronic control over the speed of the computer.

Empowering Students Through Technology

In order to enable children with handicaps to utilize these new and powerful tools to access educational opportunities it is necessary to provide appropriate training and easy access to technology. For students with handicaps, particularly those with higher cognitive functioning, we need to emphasize access to systems in our educational environments, with the primary emphasis on allowing them to utilize minimally adapted commercially available computer hardware and software.

- The following vignette is presented to illustrate technologies capacity to foster environmental access. Michael is a wheelchair-bound nine year old with cerebral palsy. He is quadriplegic and has physiologically inadequate speech production mechanisms. In spite of these physical impairments, Michael's parents and teachers were convinced of his cognitive potential. Their faith in his ability has proved to be well founded. For the past six months Michael has been using a microelectric augmentative communication system with synthesized voice and printed output. Until he had access to this technology, Michael could not "talk," write, or read. Now with the help of a simple word processing system and a complex message system, he can do all three. In the past, Michael was disenfranchised and largely disengaged at school. Now he is engaged in communication, language, and literacy learning. He has learned to use his school's electronic mail and bulletin board system to send messages to other students and others. And, for the past month, Michael has enjoyed communicating with Linda, who like Michael, recently moved from a beach community on Cape Cod to the Great Plains. Linda, who has a hearing impairment, and Michael love to reminisce, and they have both learned to write about sand dunes, surf at high tide, and lobster tails. In fact, they have co-authored an essay, "Surf and Sand," for their schools desktop publication, Essays About Our Country.

Knowledge Base

Taber (1984) identified five significant freedoms which would accrue to individuals with special needs through the effective use of technology. These include the efficient and effective use of time, the enhancement of learning processes and outcomes, greater environmental independence, and meaningful involvement in gainful employment. Such primary achievements can be expected from the judicious applications of technology on behalf of those with special needs, and each relate directly to the enhancement of communication - Taber's fifth freedom.

Access to Academics

Gregg Vanderheiden, in his article "Computers Can Play a Dual Role for Disabled Individuals" (BYTE, September, 1982) suggested: "... the immediate future promises to be an extremely exciting and productive period, which will see rapid advances in the development of both special function programs and new strategies to ensure the complete access to disabled individuals to the world of microcomputers."

If this access can be assured, then the functional disabilities currently experienced by these individuals should decrease markedly as our society moves more and more into the electronic information age. If we fail to ensure access to our computer and information-processing systems for individuals with handicaps our progress into the electronic information age will only present new barriers.

Access to Living Skills

Communication is perhaps the single most important access in educational environments. Communication is required for interacting in the classroom. Voice synthesizers allow the nonverbal person greater access to active learning opportunities by providing opportunities to interact.

Before electronic and computer technologies, the written and oral communication of students with severe handicaps was mostly limited to pointing, head shaking, and eye gazing. Interpreters would express in their own words what they thought the student intended. Now computers enable nonverbal individuals to more clearly express their thoughts through written and spoken language.

Appropriate software can enable persons with handicaps to gain control of TV, VCRs, stereos and lights. Training for environmental control can begin at an early age with the use of devices that control battery operated toys such as the Omnibox (Lahm & Behrmann, 1986).

New research and development in the field of robotics has generated excitement in the field of special education. For example, robotic arms, controlled by an individual can perform routine daily tasks such as feeding, magazine reading and telephoning.

Access to Vocational Activities

Microcomputers are being used in the vocational training curriculum and are benefiting persons with handicaps by: a) bringing assistance to individuals for less cost, b) allowing access to information available to non-handicapped peers, and c) developing intelligent prostheses that help off set the information processing problems of the student (Vanderheiden, 1983). Speech recognition is an example of improved access (Rizer & Hiner, 1985). While many adults with handicaps have some keyboard skills through the use of single fingers or head pointers, the process is long, tiresome and difficult to execute simultaneous key presses such as shift-A for capitalization. Transparent speech recognition systems allow concurrent keyboard and voice entry for virtually all software programs giving the person who is severely motorically handicapped, but verbal, access to all software and electronic information typically available to non-handicapped persons.

Rehabilitation centers have typically employed four job training approaches. They include a) computer learning for information access and general office job skills, b) specialized environments for computer programmers, c) specialized equipment as sensory aids, and d) software-based assessment and training. The first approach was used by Holleman (1986) to train college students with disability on standard computer software for personal and job use. A computer learning center was established through continuing education that has adopted an open entry/open exit policy. This allowed the students to learn at their own pace on a schedule that meets their needs. Assistants, adaptive equipment (e.g. braillers, voice synthesizers) and sign interpreters are always available to make the technology accessible. Skills learned can be transferred directly to a number of jobs and will enable students to continue to access new information through the computer.

The University of Maine at Orono has established a rehabilitation project in data processing to train students with disability to become business applications computer programmers (White & Cormier, 1986). To achieve their goal, they have simulated a business-like environment to conduct their training. Although the costs are high, they have found the project to be cost effective.

Access to Play and Recreation

Play is believed to encourage intellectual, physical, and social growth. Play adaptations specific skill training, and environmental modifications have been suggested as ways to enhance the leisure activities of children with handicaps (Haring, 1985; Murphy, Carr, & Calias, 1986 Nietupski, Hamre-Nietupski, & Ayres, 1984). It is apparent, however, that current advances in technology may also assist youngsters with special needs participate in recreational activities. Such advances include the use of communication enhancement devices, prosthetic devices, and electronic toys and robots.

Considering the impact that electronic technology is having on our entire society, it is not surprising that a similar effect is seen in the use of toys. Many electronic toys are based on recent advances in computerization. Steven Kanor is an engineer who has spent many years adapting commercially available toys to meet the operating needs of children with handicaps. His adaptations are based on each child's movement capabilities which are matched to electro-mechanical switches. After identifying the movement that is most appropriate for the youngster, Kanor designs a switch which can control a variety of adapted toys or other electronic devices. Available switches include those that are controlled by touch, light, voice, movement, position, and other stimuli.

c) Using Technology To Transfer Skills To New Settings

Technology can promote the transfer of new skills to related skills and to new settings. Generalization refers to the number of content areas, behavior, and situations affected by the initial instruction (Keogh & Glover, 1980). Methods for achieving generalization have been defined and are considered critical for education (Stokes & Baer, 1977). This section will illustrate ways that technology can serve as a tool for generalization and report research findings related to this topic.

Technology as a Tool for Generalization Across Settings

The goal of education is for skills initially learned in one context (e.g. classroom) to be used in many different contexts(e.g. home, community, employment, recreational settings). One way to reach this goal is to provide technology assistance to the students in these non-school environments. For example, a student with physical disabilities learns to use word processing in a language arts class. This same student can use word processing skills at home for personal correspondence, to obtain a job, or for creative writing as a leisure skill. These outcomes are premised on the availability of a computer system where the person lives and works. Newly learned skills would be more likely to transfer to different settings because of the technology which becomes a common tool for the pursuit of various goals.

Technology as a Tool for Generalization Across Skills.

An illustration of how technology can serve as a tool for generalization can be seen, for example with a student named Billy. Billy is presently enrolled in a regular third grade classroom with resource room instruction for his core academics. He is ten years old with physical disabilities which primarily affect his ability to write. He also has poor vision and requires large print books. Before the introduction of technology, Billy was a non-reader and his writing attempts were illegible. After training in the use of a computer and a word processing program, Billy completes class assignments and generates creative stories. Many aspects of his learning have improved as a function of his newly acquired word processing skills, such as his reading skills which have improved to the second grade level (LeFave-Ferrara, 1988).

Knowledge Base

Working with infants and young children, Behrmann and Lahm (1983) have shown that microcomputers can provide infants having limited motor abilities with the consistent control of their environment necessary for normal concept development. These researchers suggest that this environmental control should, in turn, affect language, self-concept development, communication, and social interactions. Kehr, Morrison, and Howard (1986) provided technology assistance to young children who were so physically limited that they could not play with conventional toys. By programming board games into software that is single switch activated and has synthesized speech, the children became independent in play, had increased opportunities to socialize, and also could accurately indicate their choices within that play. Improved self-esteem, mastery of part of the environment, and opportunities to develop cognitive and social skills were the major benefits achieved through computer use with those children. Other positive side effects of computer use with preschoolers has been interaction with their non-handicapped peers. Dickson (1986) found computers to be two or three times more effective at encouraging social interaction than more traditional social activities, such as snack time and playacting.

Trachtman (1984) reports that Drs. Meyers and Rosegrant used the speech synthesis capabilities of the computer in language training and found that many children who began to speak through the computer's voice rapidly started speaking themselves. This spontaneous language was not a direct goal of the program but represented the gains sometimes seen when young children are introduced to this medium.

Generalized effects have also been observed with respect to academic skills. Chiang (1986) reported transfer effects of microcomputer drills on the multiplication skills of students with learning disabilities to conventional paper and pencil tasks. Gains were significant after only a short period (i.e. 12 days) of computer use.

Two types of generalization were illustrated in the research of Farr, Hummel, Jadd, and Stein (1985). They developed a communications prothesis consisting of a morse writer system for an eight year old child with spastic quadriplegia. Generalization across skills was observed from the child's reading program to his spelling program. Generalization across settings was observed among school, home, and private therapy environments. Beneficial effects of computers that spread across related skills were also observed in participants of the Comprehensive Training and Employment Project in Hawaii (Peet, 1985). This project is an example of a post-secondary program which provided technology assistance to persons with developmental disabilities. In addition to learning to master business level word processing the program participants learned decoding skills (reading texts they word processed) and encoding written language (creating and printing texts).

In addition to increasing skills, the computer has been shown to have a positive effect on the reduction of behavior that interferes with learning. Plienis and Romanczyk (1985) conducted a comparison study of instruction delivered by adults and instruction delivered by the computer to teach a discrimination task to severely disturbed children. These researchers found that both methods were equally effective with respect to learning the task. However, the children exhibited more deviant behavior when the adult provided the instruction. Thus, a positive side effect of the computer instruction was a reduction in levels of disruptive and self-stimulatory behaviors.

A similar effect was observed by Lewis, Nail, Henschel, and Panyan (1988) who found that the use of a communication system consisting of a microcomputer, speech synthesizer, and touch tablet resulted in fewer inappropriate behaviors than the use of a language board alone. The training objective was to increase communication which was facilitated by use of the microcomputer system. Inappropriate behaviors were monitored but not directly treated in this study. Thus the improvements in the behavior can be viewed as generalization across skills as a result of the communication training with the computer system.

In conclusion, various forms of generalization have been observed in studies of technology applications in special education. Many studies report gains and growth beyond the skill(s) which was a direct focus of the investigation. By far, the consistent finding across ages was improved self-esteem (Kehr, Morrison, & Howard, 1986; Peet, 1985). Other authors have commented on the heightened motivation associated with using the computer for learning (Thorman, Gersten, Moore, & Mornat,1986; Trachtman, 1984). Future technology applications should incorporate provisions for generalization across skills and settings so that even more efficient and effective learning may occur.

BASIC PRINCIPLES FOR LEGISLATION

1. CEC and TAM would like to offer the following principles which we believe should guide the development of comprehensive legislation in the area of technology for persons with handicaps: We recommend focusing the legislation on technology assistance rather than assistive technology. The focus on technology assistance will provide a mechanism to allow a wide range of services and research on the use of technology to assist persons with handicaps of all ages gain access to the advantages of technology for learning, living, working, and recreating. We propose the following definitions:

   (A) Technology assistance means providing to individuals who have handicaps and/or disabilities any or all of the following:

      (1) information about products which are electronically operated, including microchip-based and integrated telecommunication systems, and other products which assist persons with handicaps and/or disabilities to utilize electronically operated products;

      (2) help in locating persons or public or private entities that can develop or modify such products to meet the needs of such individuals;

      (3) help in establishing or locating support systems which facilitate the effective use of such products, including but not limited to needs assessment, prescription, and customization of the product(s) and training in procedures for using the product(s);

      (4) help in finding funding sources that can be accessed to purchase such products;

(5) help in maintaining and upgrading such products;

(6) purchasing such products.

(B) Persons with handicaps and/or disabilities who could benefit from technology assistance are:

(1) persons who are eligible for special education and related services or early intervention services under the Education of the Handicapped Act; persons who are eligible for services under Titles I, VI, VII of the Rehabilitation ACT; persons with rights under Title V of the Rehabilitation Act; persons who are eligible for assistance under Titles II and XVI of the Social Security Act; and/or persons who are eligible for assistance under the Developmental Disabilities Act; and

(2) who could benefit from technological assistance which is likely to establish or improve their ability to function at home, in school, in the community, in recreational settings, on the job, and/or in other environments.

2. Many forms of technology enable individuals to communicate, learn, work, and recreate in a variety of new ways. When these advantages are limited to one setting, the power of the technology is greatly diminished both for the person and for the community. Therefore, any legislation must recognize and address the need for technology to be as transportable as possible so that persons can use it in as many situations as their life demands.

3. Technology is a powerful and robust tool that can assist persons regardless of age, type or severity of handicap. This breadth of application, however, creates problems in developing and implementing policies that foster responsible programs and services for a highly heterogenous population with diverse needs for technology assistance. Legislation must, therefore, respond on the one hand to the broad range of human needs that requires an array of frequently unique technology applications and on the other hand provide sufficient time and resources that will enable development and implementation of programs and services that responsibly serve a very diverse population.

4. There is a growing need for service delivery systems, either current or planned, to respond to requests for technology assistance. At the same time that there is systemic

response to the need, (i.e., individuals have a clear entry point to technology services), the response must be designed for each individual, not standardized for all individuals.

5. Research and development are essential for the advancement of technology and its application. To date, research has demonstrated that technology can be a powerful learning tool. Additional research is required, however, to identify new technologies and to expand our knowledge about the application and integration of technology as a learning tool. As new technology emerges, we must develop and adapt applications for assisting persons with handicaps. Therefore, we strongly recommend that any legislation contain provisions to authorize the state and federal governments the authority to fund competitively awarded research and development grants related to technology applications for persons with handicaps.

6. Education is lifelong. P.L. 99-457 has already expanded special education intervention to birth and transition programs are developing to assist persons move from schools to the world of work. Society is moving from an industrial base to an information base illustrating that new knowledge and skills are necessary for maintaining a productive life. Therefore, this legislation must recognize the important role of education throughout the lifespan from birth to the grave.

7. While legislation should appropriately contain minimum criteria, it is essential, however, that the criteria be sufficiently flexible to accommodate variation among the programs and services offered by different states and the diverse and sometimes idiosyncratic technology assistance needs required by individual states.

8. Federal Role. The federal government has a number of critical roles it must play beyond helping states. We recommend that the federal government:

   a. Coordinate and monitor common features among the states to reduce duplication of efforts (e.g., software resource guides).

   b. Assist in the process of evaluating and certifying hardware and software products developed to provide technology assistance.

c. Fund competitively awarded grants to prepare personnel to assist in the development and delivery of technology assistance. There is a continuing need to prepare personnel to competently employ technology to assist persons with handicaps to learn, work, communicate, or recreate.

d. Fund competitively awarded grants to agencies to demonstrate exemplary applications of technology assistance and systems for delivering technology assistance services. The purpose is to foster the development of model programs and applications that can be replicated across states.

e. Fund competitively awarded research and development grants in the area of technology assistance. The purpose is to identify new technologies and to develop new technology applications.

f. Encourage through incentives private sector development and marketing of technology and technology products.

g. Not develop overly prescriptive regulations that provide a disincentive to private sector firms interested in developing and marketing hardware and software devices or technology assistance delivery systems. The private sector must be an ally in the development and creation of systems to deliver technology assistance to persons with handicaps.

9. The ultimate success of technology for persons with handicaps is dependent on their participation in the selection and adoption of the system. Consumers should be members of Advisory Councils and in other leadership and decision-making roles pertaining to the provision of technology assistance.

Mr. Chairman, we thank you for the opportunity to testify and we stand ready to assist you and the Committee as you develop legislation on this most important issue.

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Senator **Harkin**. Thank you very much, Herb.

Our next witness is Denny Theesfield, a lifelong farmer from Armstrong, Iowa, who, as I said, became a paraplegic after injuries in Vietnam. Again, as I said earlier, after receiving his injuries, he didn't think that he would be able to farm again until his uncle and cousin adapted a tractor for him.

Denny, welcome to the subcommittee. It's an honor to have you here. Please go ahead.

Mr. **Theesfield**. Thank you, Mr. Chairman.

I appreciate the opportunity to appear before the subcommittee to present my views on the importance of assistive technology in rural America.

I was born and raised on a farm in northwestern Iowa. I am currently farming with the use of assistive technology. I have been involved with the Iowa Easter Seal Society's Farm Family Rehabilitation Management Program. This program helps many farmers like myself live independently and return to farming through the use of assistive technology.

After I was injured in Vietnam, I thought I could never farm again, so I had a farm sale and sold all of my machinery. Then my uncle and cousin built my first lift for me to get on and off the tractors. It was a homemade device that allowed me to start farming again.

Fifteen years ago, I did not hear of any such things as tractor lifts or hand controls. Such adaptations for farm equipment were simply not commercially available. Today, however, farmers have access to some rural technology resources. As a result of the Breaking New Ground Program at Purdue University, there is now a company that manufactures 20 different lifts for farmers with disabilities.

Even today, 90 percent of the farm equipment modifications are made locally, without blueprints or expert advice. Some of these modifications are not always safe and have resulted in further injury. It is important, therefore, that efforts to improve access to assistive technology incorporate good safety guidelines, to promote modifications that are both effective and safe.

In addition to my tractor lift and hand controls, I use automatic hitching devices to connect and disconnect my farm machinery, without having to get on and off the tractor. I have also modified my machine shed and hog operation to make it easier to get around in a wheelchair.

The cost of all these modifications and assistive devices that I use totaled about $10,000. Without these modifications, I could never have farmed again. I am fortunate. Many farmers who are affected by a traumatic injury or illness are not given the chance to consider farming again. Isolation, lack of information about the benefits of assistive technology, and the lack of access to such technology force many farmers with disabilities and their families to leave the farm. They move to the city or to another state, not by choice, but out of necessity to survive.

Returning to the home in rural America with a disability is almost impossible without the benefits of assistive technology. Most farmhouses are not wheelchair accessible. Our farmhouse did not have a downstairs bathroom, bedroom or a ramp, so we had to completely remodel the house.

The ability to live as independently as possible is extremely important to me and, I believe, to most people with disabilities. With modifications and independent living aids, I am able to perform all activities of daily living on my own. Without these modifications, I would become more dependent upon my wife, family members, and friends to help me. Such dependence can place a great deal of stress on marital and family relationships.

In many cases, this stress can result in a divorce. In other cases, families who are unable to care for the disabled family member must place that person in a nursing home or care facility. Assistive technology can play a major role in relieving the pressures of dependence by promoting maximum self-sufficiency for rural people with disabilities.

I believe that a community-based service delivery approach is best for providing access to assistive technology. Most independent living and farm modifications are built by local machine shops and friends. These devices are generally customized to meet the unique needs of a person, and frequently require refitting and adjustment.

As a result, the programs that seem to work the best for delivering useful assistive technology to farmers with disabilities are community-based and close to home. Staff with the Iowa Easter Seal Farm Program travel many miles to work with farmers and their families on their farms.

The Iowa Vocational Rehabilitation Agency has a rehabilitation engineer. His services are useful, but his location is Des Moines, Iowa, which means he is not always accessible to people who might benefit from assistive technologies but who live far from the state capital. Furthermore, he is unable to construct most of the needed modifications and devices because he lacks access to heavy machine fabrication equipment.

It is important for rural assistive technology programs to promote cooperation between state and community efforts to design, fabricate, and furnish the needed technologies. Specialized training on assistive technology is needed for the rehabilitation professions. Too few are aware of the application of assistive technologies in rural areas.

When I was in the hospital, no one ever talked to me about farming again. The medical and rehabilitation professionals viewed farming as physically demanding and, therefore, impossible to do with a severe disability. Many focused on my disability or inability, rather than maximizing my ability through the use of assistive technology. Training on what technologies are available, how modifications and devices are constructed and used, and on how to obtain them would enable these professionals to better help farmers and others with disabilities return and resume work.

Funding for assistive technology and related service delivery is extremely scarce in rural areas. There are three well-known programs in the United States that are devoted to helping disabled farmers benefit from the application of rural rehabilitation technology. They are the Iowa Easter Seal Farm Program, the Breaking New Ground Project at Purdue University in Indiana, and the

Rural and Farm Family Vocational Rehabilitation Program in Vermont.

Funding for these programs comes from private and public sources and is very hard to obtain; so difficult, in fact, that two of the three face discontinuation in the near future. I urge the subcommittee to act to preserve these valuable programs and to support new funds to initiate similar efforts serving the Nation's farmers with disabilities.

Due to budget constraints, the Iowa Vocational Rehabilitation Agency cannot provide all the money needed for work site modifications—like the structural changes I needed to modify my operation. In my case, I paid for the things I needed. However, families that cannot afford assistive technologies generally go without, which often results in further injury or illness, family separation, possibly institutionalization, and certainly wasted human potential.

Lastly, I urge the subcommittee to consider the problem that liability exposure presents for improving rural assistive technology efforts. The fear of being sued has caused many creative individuals and manufacturers to stop designing and constructing needed assistive devices and modifications. Liability insurance is very expensive and, in some cases, even costs more than the applied technology itself.

I believe that greater access to assistive technologies will help many farmers with disabilities continue to farm as a way of life. I appreciate the subcommittee's interest in this important issue, and I hope my views are helpful. I welcome any questions that you might have.

Thank you.

[The prepared statement of Mr. Theesfield follows:]

The Easter Seal Society of Iowa, Inc.
P.O. Box 4002 • Des Moines, Iowa 50333 • (515) 289-1933

TESTIMONY PRESENTED

to the

SUBCOMMITTEE ON THE HANDICAPPED

of the

COMMITTEE ON LABOR AND HUMAN RESOURCES

regarding

ASSISTIVE TECHNOLOGY IN RURAL AMERICA

on behalf of

THE EASTER SEAL SOCIETY OF IOWA'S FARM FAMILY REHABILITATION MANAGEMENT PROGRAM

Witness:

DENNY THEESFIELD
Armstrong, Iowa

Friday, May 20, 1988

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Joe Wilson, Cedar Falls

"Serving Iowans with Disabilities"

Good morning Mr. Chairman, I am Denny Theesfield from Armstrong, Iowa. I appreciate the opportunity to appear before the Subcommittee to present my views on the importance of assistive technology in rural America.

I was born and raised on a farm in northwestern Iowa. I am currently farming with the use of assistive technology. I have been involved with the Iowa Easter Seal Society's Farm Family Rehabilitation Management Program (FaRM). This program helps many farmers like myself live independently and return to farming through the use of assistive technology. I currently act as a peer counselor to other farmers with disabilities who stand to benefit from the use of assistive technology.

After I was injured in Vietnam, I thought that I could never farm again. So I had a farm sale and sold all of my machinery. Then my uncle and cousin built a lift to get me on and off tractors. It was this homemade device that allowed me to start farming again.

Fifteen years ago, I did not hear of any such things as tractor lifts or hand controls. Such adaptations for farm equipment were simply not commercially available. Today, however, farmers have access to some rural technology resources. As a result of the Breaking New Ground Program at Purdue University, there is now a company that has manufactured twenty lifts for farmers with disabilities.

Even today, 90 percent of farm equipment modifications are made locally without blueprints or expert advice. Some of these modifications are not always safe and have resulted in further injury. It is important, therefore, that efforts to improve access to assistive technology incorporate good safety guidelines to promote modifications that are both effective and safe.

In addition to my tractor lift and hand controls, I use automatic hitching devices to connect and disconnect machinery without having to get on and off the tractor. I have also modified my machine shed and hog operation to make it easier to get around in a wheelchair.

The cost of all the modifications and assistive devices that I use total about $10,000. Without these modifications, I could never have farmed again. I am fortunate. Many farmers who are affected by a traumatic injury or illness are not given the chance to consider farming again. Isolation, lack of information about the benefits of assistive technology, and lack of access to such technology force many farmers with disabilities and their families to leave the farm. They move to the city or to another state, not by choice, but of necessity to survive.

Returning to the home in rural America with a disability is almost impossible without the benefit of assistive technologies. Most farm houses are not wheelchair accessible. Our farm house did not have a downstairs bathroom, bedroom, or ramp, so we had to completely remodel the house.

The ability to live as independently as possible is extremely important to me and, I believe, to most people with disabilities. With modifications and independent living aids, I am able to perform all activities of daily living on my own. Without these modifications, I would become more dependent on my wife, family members, and friends to help me. Such dependence can place a great deal of stress on marital and family relationships. In many cases, this stress can result in divorce. In other cases, families who are unable to care for the disabled family member must place that person in a nursing home or care facility. Assistive technology can play a major role in relieving the pressures of dependence by promoting maximum self-sufficiency for rural people with disabilities.

I believe that a community-based service delivery approach is best for providing access to assistive technology. Most independent living and farm modifications are built by local machine shops and friends. The devices are generally customized to meet the unique needs of a person and frequently require refitting and adjustment. As a result, the programs that seem to work best for delivering useful assistive technologies to farmers with disabilities are community-based and close to home. Staff with the Iowa Easter Seal FaRM program travel many miles to work with farmers and their families on their farms.

The Iowa Vocational Rehabilitation Agency has a rehabilitation engineer. His services are useful. But his location - in Des Moines - means that he is not always accessible to people who might benefit from assistive technologies, but live far from the state capital. Furthermore, he is unable to construct most of the needed modifications and devices because he lacks access to heavy machine fabrication equipment. It is important for rural assistive technology programs to promote cooperation between state and community efforts to design, fabricate and furnish needed technologies.

Specialized training on assistive technology is needed for rehabilitation professionals. Too few are aware of the application of assistive technologies in rural areas. When I was in the hospital, no one ever talked to me about farming again. The medical and rehabilitation professionals viewed farming as physically demanding and, therefore, impossible to do with a severe disability. Many focused on my disability or inability, rather than on maximizing my ability through the use of assistive technology. Training on what technologies are available, how modifications and devices are constructed and used, and on how to obtain them would enable these professionals to better help farmers and others with disabilities return home and resume work.

Funding for assistive technology and related service delivery is extremely scarce in rural areas. There are three well-known programs in the United States that are devoted to helping disabled farmers benefit from the application of rural rehabilitation technology. They are the Iowa Easter Seal FaRM program, the Breaking New Ground Project at Purdue University in Indiana, and the Rural and Farm Family Vocational Rehabilitation Program in Vermont . Funding for these programs comes from private and public sources and is very hard to obtain. So difficult, in fact, that two of the three face discontinuation in the near future. I urge the Subcommittee to act to preserve these valuable programs and to support new funds to initiate similar efforts serving the nation's farmers with disabilities.

The cost of rural independent living aids, equipment adaptations, and agricultural work site modifications are primarily paid for by the family. Public and private health insurance policies rarely pay for assistive technologies and almost never cover the costs of follow-up activities.

Due to budget constraints, the Iowa Vocational Rehabilitation Agency cannot provide all the money needed for worksite modifications, like the structural changes I needed to modify my operation. In my case, I paid for the things I needed. However, families that cannot afford assistive technolgies generally go without, which often results in further injury or illness, family separation, possibly institutionalization, and, certainly, wasted human potential.

Lastly, I urge the Subcommittee to consider the problem that liability exposure presents for improving rural assistive technology efforts. The fear of being sued has caused many creative individuals and manufacturers to stop designing and constructing needed assistive devices and modifications. Liability insurance is very expensive and, in some cases, even costs more than the applied technology itself.

I believe that greater access to assistive technologies will help many farmers with disabilities continue to farm as a way of life. I appreciate the Subcommittee's interest in this important issue. I hope that my views are helpful and I welcome any questions that you might have.

Thank you.

Senator **Harkin**. Denny, thank you very much for your fine testimony.

Tom O'Bryant is Director of Equal Opportunity affairs with the Champion International Corporation. He has served as Chairman of the Employer Committee of the President's Committee on Employment of the Handicapped for nearly three years.

Tom, welcome to the subcommittee, and please proceed.

Mr. **O'Bryant**. Thank you, Mr. Chairman.

I want to thank you for conducting these hearings on technology and disability, and for giving me the opportunity to participate.

As you previously stated, I am the Director of Equal Opportunity Affairs for Champion International, headquartered in Stamford, Connecticut. In addition, I serve as Chairman of the Employer Committee of the President's Committee on Employment of People with Disabilities. It is in this latter capacity that I appear before you today.

By way of further introduction, the Employer Committee of the President's Committee consists of 29 companies, mostly large, representing a cross-section of business and industry from across the country. Our programs and activities include and involve countless additional large and small employers.

In the almost three years that I have served as Chairman of the Employer Committee, I have come to know and work with literally hundreds of employers nationally. Additionally, as a member of the Connecticut Governor's Committee on Employment of the Handicapped, I work with employers throughout my home State. Consequently, I have had the privilege of experiencing and observing the impact that technology has on the employment of people with disabilities at the local, State and national level.

As a result, I can tell you without any hesitation that technology—and I would like to emphasize right from the start that I mean both high and low technology—has and can make the major difference between the employment and unemployment of many people with disabilities.

Of course, there are individuals with disabilities who do not need technology or assistive devices in order to function independently and productively in employment. Thus, we do not want to create a new stereotype, one that says that all individuals with disabilities must have the benefit of technological devices or services in order to be gainfully employed.

However, reality tells us that many individuals with disabilities can become more independent, can become employed, advanced in employment, and more productive if they are afforded the opportunity to benefit from technological services and devices.

For many people with disabilities, technology offers the opportunity to prepare for and excel in a far greater number of jobs. Technology enables employees with disabilities to compete for and to expect the same in-service training and career-advancement opportunities as are available to other employees.

In addition, individuals who are injured while on or off the job, or who become disabled for any reason, can now return to work, and often to their old jobs, because of technology. And individuals with very severe disabilities, many of whom who have been considered to be unemployable, are now able to obtain employment and to succeed as valuable, contributing employees.

With the current high interest in technology and the rapid advances that are being made, it is my belief that technology will enable many more people with disabilities to be employed and to function independently. As I say this, however, I recognize that this will only happen if technology is generally known and readily available to individuals with disabilities and to employers. That is key.

I could say much more philosophically about this subject, but it might be more meaningful if I simply give a few examples of how technology has made the difference between employment, unemployment or under-employment. Let me just cite a few case studies that I have had the pleasure of learning about.

In Iowa, for example, an engineer with multiple sclerosis began having difficulty reading her computer monitor due to her diminishing eyesight. A special lens cover was installed over her computer screen, enlarging the print and reducing the glare. This enabled her to continue her work while she received specialized training to perform without her sight. A simple device saved a job.

In Vermont, a radio dispatcher with retinitis pigmentosa needed to be able to dial a great many telephone numbers in a hurry. The provision of a personal computer with an automatic dialing modem and a voice synthesis system allowed the dispatcher to handle the calls in a timely manner.

Out in Oregon, a logger lost two fingers on his dominant hand. With the use of a glove with a built-in wrist support, he was able to continue using his chain saw, thereby retaining his job.

In Connecticut, my home state, a sales agent who became paralyzed because of a broken neck, was able to continue his career after he was provided with a drafting table, a page turner and a pressure-sensitive tape recorder.

In Illinois, a barber incurred a knee injury which prevented him from standing more than 50 percent of the day. A stand-up wheelchair allowed him to continue his job on a full time basis.

These are only a few examples; I could give you dozens more. They demonstrate all levels of technology, including high, low, and in the case of the glove, we might even say no technology. Yet, even in this instance, technology was very important. It was used to develop the glove which, in addition to providing support, had to be temperature sensitive. This example illustrates very well that we are really talking about more than technology.

None of the successes listed above could have happened were it not for the presence of a skilled and knowledgeable individual who was available to either the employer, the employee, or both, and who could find—or in the case of the glove, develop—an individualized, technological solution to the challenge presented by the disability.

As important as it currently is that individuals with disabilities and their employers have the benefit of technological services and devices, it will be even more important in the future. People with disabilities are now being aggressively sought out for employment by employers who are currently experiencing labor shortages. McDonalds, Burger King, Kentucky Fried Chicken, and Marriott all have developed programs which train individuals to work in the service industry. There will be more selective training and recruitment programs like these in the future.

Additionally, I submit that employers from all occupational areas will soon begin to look towards people with disabilities to fill the empty positions that labor market futurists are predicting will occur.

Many of the jobs that will be coming available will be in the small business sector. In the past, we have looked to the large companies like AT&T, IBM, and General Motors to provide the jobs and the technological accommodations; and they have. Now, this is changing.

Last year, Fortune 1000 companies lost 1.5 million jobs; and this year it is estimated they will lose an additional 2 million. While in 1985, employers hired 2 million workers, more than half of these were hired by companies with fewer than 100 employees. An additional 29 percent secured employment with companies of 100 to 1,000 workers, and only 18 percent were employed by firms with 1,000 or more employees.

Small employers generally are not aware of the programs and services available to individuals with disabilities, nor the devices and accommodations that enable them to compete and perform.

Nor in many instances, do they have the financial resources to provide technological or other accommodation devices as larger companies do. Thus, it will be crucial that any technology initiative include mechanisms to address this issue.

Thank you.

[The prepared statement of Mr. O'Bryant follows:]

STATEMENT FOR THE RECORD

BY

TOM O'BRYANT

DIRECTOR

EQUAL OPPORTUNITY AFFAIRS

CHAMPION INTERNATIONAL CORPORATION

STAMFORD, CONNECTICUT

AND

CHAIRMAN

EMPLOYER COMMITTEE

PRESIDENT'S COMMITTEE ON EMPLOYMENT
OF PEOPLE WITH DISABILITIES

FRIDAY, MAY 20, 1988

GOOD MORNING, MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE ON THE HANDICAPPED.

I WANT TO THANK YOU FOR CONDUCTING THESE HEARINGS ON TECHNOLOGY AND DISABILITY AND FOR GIVING ME THE OPPORTUNITY TO PARTICIPATE.

I AM THE DIRECTOR OF EQUAL OPPORTUNITY AFFAIRS FOR CHAMPION INTERNATIONAL CORPORATION, HEAD-QUARTERED IN STAMFORD CONNECTICUT. IN ADDITION I SERVE AS THE CHAIRMAN OF THE EMPLOYER COMMITTEE OF THE PRESIDENT'S COMMITTEE ON EMPLOYMENT OF PEOPLE WITH DISABILITIES. IT'S IN THIS LATTER CAPACITY THAT I APPEAR BEFORE YOU TODAY.

BY WAY OF FURTHER INTRODUCTION, THE EMPLOYER COMMITTEE OF THE PRESIDENT'S COMMITTEE CONSISTS OF 29 COMPANIES, MOSTLY LARGE, REPRESENTING A CROSS SECTION OF BUSINESS AND INDUSTRY FROM ACROSS THE COUNTRY. OUR PROGRAMS AND ACTIVITIES INCLUDE AND INVOLVE COUNTLESS ADDITIONAL LARGE AND SMALL EMPLOYERS.
IN THE ALMOST THREE YEARS I HAVE SERVED AS CHAIRMAN OF THE EMPLOYER COMMITTEE, I HAVE COME TO KNOW AND WORK WITH LITERALLY HUNDREDS OF EMPLOYERS NATIONWIDE. ADDITIONALLY, AS A MEMBER OF THE CONNECTICUT GOVERNOR'S COMMITTEE ON EMPLOYYMENT OF THE HANDICAPPED, I WORK WITH EMPLOYERS THROUGHOUT MY HOME STATE. CONSEQUENTLY, I'VE HAD THE

PRIVILEGE OF EXPERIENCING AND OBSERVING THE IMPACT THAT TECHNOLOGY HAS ON THE EMPLOYMENT OF PEOPLE WITH DISABILITIES AT THE LOCAL, STATE AND NATIONAL LEVEL.

AS A RESULT, I CAN TELL YOU WITHOUT ANY HESITATION THAT TECHNOLOGY, AND I WOULD LIKE TO EMPHASIZE RIGHT FROM THE START THAT I MEAN BOTH HIGH AND LOW TECHNOLOGY, HAS AND CAN MAKE THE MAJOR DIFFERENCE BETWEEN THE EMPLOYMENT AND UNEMPLOYMENT OF MANY PEOPLE WITH DISABILITIES.

OF COURSE, THERE ARE INDIVIDUALS WITH DISABILITIES WHO DO NOT NEED TECHNOLOGY OR ASSISTIVE DEVICES IN ORDER TO FUNCTION INDEPENDENTLY AND PRODUCTIVELY IN EMPLOYMENT. THUS, WE DO NOT WANT TO CREATE A NEW STEREOTYPE, ONE THAT SAYS THAT ALL INDIVIDUALS WITH DISABILITIES MUST HAVE THE BENEFIT OF TECHNOLOGICAL DEVICES OR SERVICES IN ORDER TO BE GAINFULLY EMPLOYED.

HOWEVER, REALITY TELLS US THAT MANY INDIVIDUALS WITH DISABILITIES CAN BECOME MORE INDEPENDENT, CAN BECOME EMPLOYED, ADVANCED IN EMPLOYMENT, AND MORE PRODUCTIVE IF THEY ARE AFFORDED THE OPPORTUNITY TO BENEFIT FROM TECHNOLOGICAL

SERVICES AND DEVICES. FOR MANY PERSONS WITH DISABILITIES TECHNOLOGY OFFERS THE OPPORTUNITY TO PREPARE FOR AND EXCEL IN A FAR GREATER NUMBER OF JOBS. TECHNOLOGY ENABLES EMPLOYEES WITH DISABILITIES TO COMPETE FOR AND TO EXPECT THE SAME IN-SERVICE TRAINING AND CAREER ADVANCEMENT OPPORTUNITIES AS ARE AVAILABLE TO OTHER EMPLOYEES. IN ADDITION, INDIVIDUALS WHO ARE INJURED WHILE ON OR OFF THE JOB, OR WHO BECOME DISABLED FOR ANY REASON, CAN NOW RETURN TO WORK, AND OFTEN TO THEIR OLD JOBS, BECAUSE OF TECHNOLOGY. AND, INDIVIDUALS WITH VERY SEVERE DISABILITIES, MANY OF WHOM HAVE BEEN CONSIDERED TO BE UNEMPLOYABLE, ARE NOW ABLE TO OBTAIN EMPLOYMENT AND TO SUCCEED AS VALUABLE, CONTRIBUTING EMPLOYEES. WITH THE CURRENT HIGH DEGREE OF INTEREST IN TECHNOLOGY AND THE RAPID ADVANCES THAT ARE BEING MADE, IT IS MY BELIEF THAT TECHNOLOGY WILL ENABLE MANY MORE PEOPLE WITH DISABILITIES TO BE EMPLOYED AND TO FUNCTION INDEPENDENTLY. AS I SAY THIS, HOWEVER, I RECOGNIZE THAT THIS WILL ONLY HAPPEN IF TECHNOLOGY IS GENERALLY KNOWN AND READILY AVAILABLE TO INDIVIDUALS WITH DISABILITIES AND TO EMPLOYERS. THAT'S KEY.

I COULD SAY MUCH MORE PHILOSOPHICALLY, ABOUT THIS SUBJECT. BUT IT MIGHT BE MORE MEANINGFUL IF I SIMPLY GIVE A FEW EXAMPLES OF HOW TECHNOLOGY HAS MADE THE DIFFERENCE BETWEEN

EMPLOYMENT AND UNEMPLOYMENT OR UNDER-EMPLOYMENT. LET ME JUST CITE A FEW CASE STUDIES THAT I HAVE HAD THE PLEASURE OF LEARNING ABOUT.

IN IOWA, FOR EXAMPLE, AN ENGINEER WITH MULTIPLE SCLEROSIS, BEGAN HAVING DIFFICULTY READING HER COMPUTER MONITOR DUE TO DIMINISHING EYESIGHT. A SPECIAL LENS COVER WAS INSTALLED OVER HER COMPUTER SCREEN, ENLARGING THE PRINT AND REDUCING THE GLARE. THIS ENABLED HER TO CONTINUE HER WORK WHILE SHE RECEIVED SPECIALIZED TRAINING TO PERFORM WITHOUT HER SIGHT. A SIMPLE DEVICE SAVED A JOB.

IN VERMONT, A RADIO DISPATCHER WITH RETINITIS PIGMENTOSA NEEDED TO BE ABLE TO DIAL A GREAT MANY TELEPHONE NUMBERS IN A HURRY. THE PROVISION OF A PERSONAL COMPUTER WITH AN AUTOMATIC DIALING MODEM AND A VOICE SYNTHESIS SYSTEM ALLOWED THE DISPATCHER TO HANDLE THE CALLS IN A TIMELY MANNER.

OUT IN OREGON, A LOGGER LOST TWO FINGERS ON HIS DOMINANT HAND. WITH THE USE OF A GLOVE WITH A BUILT-IN WRIST SUPPORT, HE WAS ABLE TO CONTINUE USING HIS CHAIN SAW, THEREBY RETAINING HIS JOB.

IN CONNECTICUT, MY HOME STATE, A SALES AGENT WHO BECAME PARALYZED BECAUSE OF A BROKEN NECK, WAS ABLE TO CONTINUE HIS CAREER AFTER HE WAS PROVIDED WITH A DRAFTING TABLE, A PAGE TURNER AND A PRESSURE SENSITIVE TAPE RECORDER.

AND IN ILLINOIS A BARBER INCURRED A KNEE INJURY WHICH PREVENTED HIM FROM STANDING MORE THAN 50% OF THE DAY. A "STAND-UP' WHEELCHAIR ALLOWED HIM TO CONTINUE HIS JOB ON A FULL TIME BASIS.

THESE ARE ONLY A FEW EXAMPLES. I COULD GIVE YOU DOZENS MORE. THEY DEMONSTRATE ALL LEVELS OF TECHNOLOGY, INCLUDING HIGH, LOW, AND IN THE CASE OF THE GLOVE, WE MIGHT EVEN SAY NO TECHNOLOGY. YET, EVEN IN THIS INSTANCE, TECHNOLOGY WAS VERY IMPORTANT. IT WAS USED TO DEVELOP THE GLOVE WHICH, IN ADDITION TO PROVIDING SUPPORT, HAD TO BE TEMPERATURE SENSITIVE. THIS EXAMPLE ILLUSTRATES VERY WELL THAT WE REALLY ARE TALKING ABOUT MORE THAN TECHNOLOGY. NONE OF THE SUCCESSES LISTED ABOVE COULD HAVE HAPPENED WERE IT NOT FOR THE PRESENCE OF A SKILLED AND KNOWLEDGEABLE INDIVIDUAL WHO WAS AVAILABLE TO EITHER THE EMPLOYER OR THE EMPLOYEE OR BOTH, AND WHO COULD FIND, OR IN THE CASE OF THE GLOVE DEVELOP, AN INDIVIDUALIZED TECHNOLOGICAL SOLUTION TO THE CHALLENGE PRESENTED BY THE DISABILITY.

IT SO HAPPENS THAT ALL OF THE ABOVE ACCOMMODATIONS WERE MADE THROUGH THE PRESIDENT'S COMMITTEE'S JOB ACCOMMODATION NETWORK. JAN WAS DEVELOPED BY THE EMPLOYER COMMITTEE AND IS PRESENTLY FUNDED BY THE REHABILITATION SERVICES ADMINISTRATION AND THE NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH. IT IS OPERATED THROUGH A CONTRACT WITH WEST VIRGINIA UNIVERSITY. JAN HAS ESTABLISHED AN OUTSTANDING RECORD OF WORKING WITH EMPLOYERS AND EMPLOYEES TO LOCATE OR DEVELOP TECHNOLOGICAL ANSWERS TO JOB ACCOMMODATIONS. ALTHOUGH, JAN IS A LIMITED SERVICE AS CURRENTLY FORMATTED AND FUNDED, NEVERTHELESS, IT DOES PROVIDE US WITH A GOOD EXAMPLE OF WHAT IS NEEDED AND WHAT CAN BE DONE ON THE MUCH LARGER SCALE SUGGESTED BY THESE HEARINGS.

AS IMPORTANT AS IT CURRENTLY IS THAT INDIVIDUALS WITH DISABILITIES AND THEIR EMPLOYERS HAVE THE BENEFIT OF TECHNOLOGICAL SERVICES AND DEVICES, IT WILL BE EVEN MORE IMPORTANT IN THE FUTURE. PEOPLE WITH DISABILITIES ARE NOW BEING AGGRESSIVELY SOUGHT OUT FOR EMPLOYMENT BY EMPLOYER EXPERIENCING LABOR SUPPLY SHORTAGES. MCDONALDS, BURGER KING, KENTUCKY FRIED CHICKEN, AND MARRIOTT ALL HAVE DEVELOPED PROGRAMS WHICH TRAIN INDIVUALS TO WORK IN THE SERVICE INDUSTRY. THERE WILL BE MORE SELECTIVE TRAINING AND RECRUITMENT PROGRAMS LIKE THESE IN THE FUTURE. ADDITIONALLY, I SUBMIT THAT EMPLOYERS FROM ALL OCCUPATIONAL AREAS WILL SOON BEGIN TO LOOK TOWARDS PEOPLE WITH DISABILITIES TO FILL THE EMPTY POSITIONS THAT LABOR MARKET FUTURISTS ARE PREDICTING WILL OCCUR.

MANY OF THE JOBS THAT WILL BECOMING AVAILABLE WILL BE IN THE SMALL BUSINESS SECTOR. IN THE PAST WE HAVE LOOKED TO THE LARGE COMPANIES LIKE AT&T, IBM, AND GENERAL MOTORS TO PROVIDE THE JOBS AND THE TECHNOLOGICAL ACCOMMODATIONS. AND, THEY HAVE.

NOW, THIS IS CHANGING.

LAST YEAR THE FORTUNE 1000 COMPANIES LOST 1.5 MILLION JOBS AND THIS YEAR IT IS ESTIMATED THAT THEY WILL LOSE AN ADDITIONAL 2 MILLION.

WHILE IN 1985, EMPLOYERS HIRED 2 MILLION WORKERS, MORE THAN HALF OF THESE WERE HIRED BY COMPANIES WITH FEWER THAN 100 EMPLOYEES. AN ADDITIONAL 29% SECURED EMPLOYMENT WITH COMPANIES OF 100 TO 1000 WORKERS. ONLY 18% WERE EMPLOYED BY FIRMS WITH 1000 OR MORE EMPLOYEES.

SMALL EMPLOYERS GENERALLY ARE NOT AS AWARE OF THE PROGRAMS AND SERVICES AVAILABLE TO INDIVIDUALS WITH DISABILITIES NOR THE DEVICES AND ACCOMMODATIONS THAT ENABLE THEM TO COMPETE AND PERFORM. NOR DO THEY HAVE THE FINANCIAL RESOURCES TO PROVIDE TECHNOLOGICAL OR OTHER ACCOMMODATION DEVICES AS THE LARGER COMPANIES DO. THUS IT WILL BE CRUCIAL THAT ANY TECHNOLOGY INITIATIVE INCLUDE MECHANISMS TO ADDRESS THIS ISSUE.

THERE IS YET ANOTHER COMPELLING POINT SUPPORTING A TECHNOLOGY INITIATIVE. AS WE BEGIN CONSIDERING THE "AMERICANS WITH DISABILITIES ACT" WE MUST BEGIN TO LOOK FORWARD TO A TIME WHEN THERE WILL BE AN EVEN GREATER DEMAND FOR QUALIFIED WORKERS WITH DISABILITIES. THE SUCCESS OR FAILURE OF CIVIL RIGHTS LEGISLATION WILL HINGE ON THE AVAILABILITY OF BOTH TECHNOLOGY AND A SERVICE DELIVERY SYSTEM TO APPLY IT IN INDIVIDUAL CIRCUMSTANCES.

IN SHORT, MY OBSERVATIONS AS AN EMPLOYER LEAD ME TO BELIEVE THAT TECHNOLOGY AND THE SUPPORT OF IT'S DELIVERY IS A KEY INGREDIENT IN A SOCIETY BOTH POLITICALLY AND ECONOMICALLY COMMITTED TO FULL INTEGRATION OF PEOPLE WITH DISABILITIES IN ALL PHASES OF SOCIETY, INCLUDING EMPLOYMENT. I APPLAUD THIS COMMITTEE FOR ITS VISION AND LEADERSHIP.

Senator **Harkin**. Tom, thank you very much for a fine statement.

All of you have raised significant points which I would like to have some time to cover in questions.

I want to welcome our distinguished colleague from Connecticut, Senator Weicker, to the subcommittee.

Senator **Weicker**. Mr. Chairman, thank you very much. I have an opening statement which has been placed into the record.

It's good to have the entire panel before us, especially Tom, who represents a company that has been very advanced in the area of working with those with disabilities. Please convey my best to Andy Siegler, Mr. Heiss and the whole group up there. We're very proud of Champion in the State of Connecticut, and very proud especially of the efforts that you're in charge of and that you have so eloquently testified to here today.

Senator **Harkin**. Thank you very much. Do you have any questions for them?

Senator **Weicker**. No.

Senator **Harkin**. Let me begin with some questions; I have at least a couple for each of you.

Dr. Rieth, I want to get into this issue of centers and distribution systems. We are considering making funds available to states for systemic changes and for the actual purchase of devices and for the distribution to users.

To what extent might additional funding for the purchase of these devices raise the expectations of parents and schools that more assistive devices would be available? Then, again, if expectations are raised, would this be a good result or not? Would it then increase demands that assistive devices and services be included in the individualized students' education plans?

Again, as we proceed on this, if we then raise the expectations, what happens out there when those expectations are raised?

Dr. **Rieth**. In this case, I would support the notion of raising expectations in the sense that part of what the Bill addresses is to disseminate more information about the availability and the power of technology.

However, I think you did address a very good point in the sense of what do we do with those expectations, and then how does that impact on individual education plans. Based on the reading of the legislation, I think it is handled very adequately in the legislation in terms of basically establishing a balance.

That is we wanted to raise the person's expectation, but that does not necessarily mean that the schools must provide a technology device for each student. The school system may be able to work cooperatively with parents to enable them to find other resources to provide the technology for the person.

So in this case, what we are saying is that, yes, we want to increase people's knowledge so that they are aware of this as a learning tool to facilitate learning; but at the same time do not necessarily mandate the requirement that the school system must provide technology assistance for each handicapped student.

Senator **Harkin**. You mentioned briefly in your testimony that on the principles for legislation, you said, "We recommend focusing the legislation on technology assistance rather than assistive technology."

You're not just playing with words there, are you? What does that mean?

Dr. **Rieth**. Well, I think to us it conveys a broader meaning, that the technology does provide assistance to open up additional opportunity, to enhance opportunity through learning, through social interaction, through communication, vocational-occupational opportunities.

It also encompasses, from our perspective, the issue of the human assistance to enable the person with disabilities to use the technology to compensate for their disability. Technology assistance also encompassess a broad array of technology, not simply assistive devices alone.

Senator **Harkin**. So, you see technology assistance as a broad array of things?

Dr. **Rieth**. Right.

Senator **Harkin**. A broader array. Assistive technology is just a device to give to someone?

Dr. **Rieth**. Conceivably.

Senator **Harkin**. I see. I understand.

One last thing for you is this. You say assistive technology services should be available from birth to death to a whole range of people with disabilities; and you define the eligible population by referencing certain Federal laws that we have passed here.

Do those laws exclude anyone? Are there groups, or individuals out there who are excluded from those laws right now?

Dr. **Rieth**. To my knowledge, they are fairly inclusive, and it is our position that the legislation should be inclusive rather than exclusive. Indeed, if it isn't sufficiently inclusive of different groups with disabilities, then it should be broadened to include them.

Senator **Harkin**. Mr. O'Bryant, you are right when you are talking about small businesses. That is what we see as the biggest creator of new jobs in America. I think that is where we are seeing real growth in America, the smaller firms. Yet, these are the ones that are the least capitalized; they have the least ability to do the kind of things that we are talking about here in terms of assistance.

How are we going to enable those companies to introduce technological improvements into the work place? How are we going to do it? Is it going to be through tax incentives? How do you think a small business person, with fewer than 100 employees, operating on a margin, is going to get the financial resources to do this?

Mr. **O'Bryant**. Mr. Chairman, I think you have hit upon the major concern which is that the lack of financial resources available to many of the small businesses. I think this will almost preclude their taking advantage of these technological advances without something like a tax credit or some other type of local resource to assist them in coping with the financial impact.

Senator **Harkin**. What's available right now? If I'm a small business person and I wish to modify the work place to enable certain handicapped individuals to work there, are there tax advantages right now, any tax benefits?

Mr. O'BRYANT. You can get, I believe it's up to a $35,000 tax deduction for any type of modifications that are made at your work place.

Senator HARKIN. $35,000 credit?

Mr. O'BRYANT. Deduction.

Senator HARKIN. That's a direct payment.

Mr. O'BRYANT. No, it's a tax deduction.

Senator HARKIN. Well, but a tax deduction, you either pay Uncle Sam or you pay it out; one of the two.

Mr. O'BRYANT. Also, there is the Targeted Jobs Tax Credit Program for those individuals who qualify, which would give some advantage to—not just a small employer, but to all employers who participate in this of programs.

Senator HARKIN. That is just to one employer; right?

Mr. O'BRYANT. That is correct.

Senator HARKIN. For the entire work place?

Mr. O'BRYANT. For the entire work place; and that would be the same thing even for a corporation.

Senator HARKIN. So that would be the same credit for IBM as it would be for Champion?

Mr. O'BRYANT. That is my understanding, yes, sir.

Senator HARKIN. It seems that we ought to take a look at that, too.

Again getting back to the small businesses, many of the small businesses are not very top-heavy in terms of management. They don't have a lot of different departments that a large conglomerate or corporation might have. Yet, it's important, as you point out, that these employers learn about assistive technology.

What strategies that right now might be directed at larger employers could be used for small employers, or what could we do to bring them up to speed on what could be done? As I said, they don't have departments that take care of that. Usually, you're talking about a few people running a small business. What can we do?

Mr. O'BRYANT. Mr. Chairman, the Employer Committee struggled with that issue recognizing that is where employment opportunities will be in the future, and how can we best access small employers. And as you have adequately pointed out, most do not have human resource staffs and do not have personnel that can attend national meetings, to become knowledgeable about these advances.

One of the strategies that I think could be employed to access the small business is through professional, and trade organizations. Maybe we should target those organizations and, through their magazines or periodicals, share this information. Beyond that, I think it's going to take a local effort by organizations and agencies that deal with the disabled to, on a face-to-face, one-on-one basis, try to acclimate the small employer to the programs that are available and to the advantages of utilizing persons with disabilities.

Senator HARKIN. Is there a role for the Federal Government in this, in terms of educating employers or at least letting them know what's available, what could be done? Is there a role for the Federal Government?

Mr. O'BRYANT. I think there's a role, but I think it will be a much more difficult role than it has been in the past, where the primary targets have been the larger corporations.

Senator **Harkin**. It's much more difficult when you dealing with thousands of small employers.

Do you think that a bill that accelerates the tax writeoffs would help small and large companies that buy assistive equipment?

Mr. **O'Bryant**. I think such a bill would have a positive impact for all sized companies. But it is my belief that it would be particularly advantageous to the small and to the medium sized companies.

Senator **Harkin**. Giving them a faster writeoff?

Mr. **O'Bryant**. Yes, sir.

Senator **Harkin**. Of course, the best is a tax credit.

Mr. **O'Bryant**. That's correct.

Senator **Harkin**. But that is always the toughest thing to get through because that is, as I said, a direct take-away from Uncle Sam. But a tax writeoff might be coupled with that, an accelerated tax writeoff coupled with the credit up front.

Mr. **O'Bryant**. It would certainly be a positive step; yes, sir.

Senator **Harkin**. I just wanted you to know that I do have a bill in, S. 1806, that basically provides for a faster writeoff. I just wanted to get from you how important that might be for the small business person.

Mr. **O'Bryant**. I think it would be very important.

Senator **Harkin**. I don't know if we have a tax bill this year, but maybe next year when we get a tax bill, we can get that done.

I have a question for Denny. Denny, you pointed out the real difficulty of getting services to people in rural areas; the fact that someone is located in Des Moines and you are clear up in northwest Iowa.

Do you think it would be good to have a special program for making sure that those services are provided to rural Americans? We keep talking about all these services, technology assistance rather than assistive technology and all the various support programs. Does there need to be a special branch of this for rural areas?

Mr. **Theesfield**. I really believe so because farming is kind of a breed all by itself.

Senator **Harkin**. There are a lot of farmers who have bad back problems and this sort of thing, who need somebody who can come out and tell them how to put in an air seat or a hydraulic seat.

It isn't all people in wheelchairs who need this kind of assistance. It's amputees, for example; there's people who lose a leg or they lose an arm, and they need a hydraulic lift for their tractor, that somebody in the city would probably not know anything about. So we need somebody who can come right out to the farm and deal one-on-one with the person on the farm is different. This from the person who needs a ramp or something in their house, we are talking about two different kinds of technology.

Mr. **Theesfield**. Yes.

Senator **Harkin**. Also, you are talking about someone servicing a person who is a long ways away. It may take time to drive out there and drive back. Again, that's why I'm trying to decide, and we're all trying to decide, how do we arrange this and set this up.

People talk about centers; well, centers might be all right in some areas, but I don't know that it would work in Iowa where everything is so dispersed out there in the rural areas. Maybe we need a different type of delivery system in a rural area.

Mr. **THEESFIELD**. We have Terry Willkomm who is in charge of the farm program out of Ankeny, Iowa, and she started out with like 18 people, and now she's trying to service something like 150 people, and doing it all herself. They're just running her ragged. I think last month she got eight new individuals themselves that needed help. There's no way she can do an advantage to all of us.

I live 180 miles from her, and I've been fortunate that I've had a good relationship with her. She has helped me an awful lot, and I hope I can help her back the same way.

Senator **HARKIN**. That's what we mean about raising expectations. When people start finding out about that, they're saying, "Wait a minute. There are things out there to help us." I think that's good, that we raise those expectations out there. It forces us to start doing some things.

Let me ask you another thing. How much help has the Veterans Administration been?

Mr. **THEESFIELD**. I haven't gotten any help out of the VA.

Senator **HARKIN**. What?

Mr. **THEESFIELD**. Not for anything that I've done on the farm. But I've never asked for it either.

Senator **HARKIN**. I find that very odd. You haven't had anything advanced——

Mr. **THEESFIELD**. They have never once said anything to me. They know that I farm. The only complaint they have is that I go through too many wheelchairs on the farm.

Senator **HARKIN**. They do provide you with wheelchairs. But they have not come out in any way to help with your occupation?

Mr. **THEESFIELD**. No, sir.

Senator **HARKIN**. What else have they done? They help you with the chair. What else have they done?

Mr. **THEESFIELD**. They help me with my wheelchair, and at the time when I first bought my acreage—at that time, it was $12,500 that they put towards something. That was the maximum that they would pay. If I bought something worth $50,000, they would still only pay $12,500, and it had to be at least $25,000 that I bought in order for them to come up with $12,500. But that was back in 1971 that I purchased that.

They do provide the adaptive equipment that I need on my automobile, and they provide my hand controls for that, and they give me all my medical supplies.

Senator **HARKIN**. How about adaptations for your tractor; your hand controls for your tractor?

Mr. **THEESFIELD**. I make all them out of pieces of steel. That's all hand-fabricated stuff. But as far as my lifts for my tractors and all that, I have paid for all that myself.

Senator **HARKIN**. But you never asked them?

Mr. **THEESFIELD**. No, I never did.

Senator **HARKIN**. So we don't know whether they would have or not?

Mr. **THEESFIELD**. No. I did ask for an electric wheelchair one time, and I got turned down for that. They said as long as I had my arms, I didn't need one—which I can't deny that. There's probably people that maybe do need it worse, but there are times that it would sure be nice, too.

Senator **Harkin**. Do you work through the VA out of Des Moines?

Mr. **Theesfield**. Out of Des Moines, yes.

Senator **Harkin**. Thank you Denny.

Sally, where is the Lekotek Center in Iowa?

Ms. **DeVincentis**. It's in Cedar Rapids.

Senator **Harkin**. Would you give my staff the information on it? I'd like to take a look at it.

Ms. **DeVincentis**. Sure. Actually, they have a couple of extensions. That's where their main one is, but they have several extensions, too. They have one in Iowa City.

It was started originally by the Quaker Oats Company that has their plants there. They gave the funding originally.

Senator **Harkin**. Let me ask you this. Is there any way that the Lekotek Centers operate differently in rural areas than in other areas? Do they have different ways of operating?

Ms. **DeVincentis**. They do; they operate—they take on the complexion of the community. So an intercity Lekotek is probably going to be a lot different than a rural Lekotek. Probably, in a rural Lekotek, the Lekotek leader does a lot of traveling. Frequently, they do only home visits in rural areas. So it is quite different.

Senator **Harkin**. You have said that we need some kind of backup centers. There are a lot of different approaches to doing this. If we can only afford a few, how should they be? Should they focus on functional limitations related to work or education, or on specific disabilities, or should they be all-purpose type of centers? How would you envision these centers?

Ms. **DeVincentis**. None of the above. I don't like the idea of focusing on disability. We have talked a little bit about this. It should be on functional needs. I think perhaps something like four centers on sensory needs, physical needs, communication needs, and four centers that really specialize in the areas that are very interrelated.

I think all-purpose, you just dissipate it too far, across too many people. If you had those, really, research and development areas that could feed information around the country, I think there's lots of inventive ways to have centers locally that really respond to local needs, but they need that backup service. So I would like to see those four or five really major centers that have very clear interests.

Senator **Harkin**. Thank you very much.

Does anybody else have any last things that they want to add before I dismiss this panel?

Herb, did you have anything else?

Dr. **Rieth**. No, sir.

Senator **Harkin**. Thank you all very much for coming. I appreciate it.

Our second panel will discuss the funding of assistive devices, reimbursement and cost and benefits.

Our first witness will be Dr. Barbara Boardman, analyst with the Office of Technology Assessment. Dr. Boardman will address the cost and benefits of assistive technology. Then we will hear from

Dr. Steve White, Director of the Reimbursement Policy Division with the American-Speech-Language-Hearing Association. Next will be Mary Pat Radabaugh, Director of the IBM National Support Center for Persons with Disabilities.

Could I ask Larry Scadden also to join with Panel Two, because in the interest of time, we're going to have to combine panels II and III.

Larry Scadden is the Director of the Rehabilitation and Engineering Center of the Electronic Industries Foundation. Dr. Scadden will present information on research and development of assistive technology and address the special concerns of small businesses.

Again, we welcome you all to the subcommittee. As I said before, your statements will be made a part of the record in their entirety. Again, in the interest of time, I will ask you to try to sum up your remarks in 5 to 7 minutes. I will point to my watch after about 5 minutes, and then you will know you've got a couple more minutes after that

Dr. Boardman, welcome to the subcommittee. Please proceed.

STATEMENTS OF BARBARA BOARDMAN, M.D., OFFICE OF TECHNOLOGY ASSESSMENT, WASHINGTON, DC; STEVE WHITE, DIRECTOR, REIMBURSEMENT POLICY DIVISION, AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION, ROCKVILLE, MD; MARY PAT RADABAUGH, MANAGER, IBM NATIONAL SUPPORT CENTER FOR PERSONS WITH DISABILITIES, ATLANTA, GA; AND LARRY SCADDEN, DIRECTOR, REHABILITATION AND ENGINEERING CENTER, ELECTRONIC INDUSTRIES FOUNDATION, WASHINGTON, DC

Dr. **Boardman**. Thank you. I'm Dr. Boardman. I'm a physician and senior analyst with the Office of Technology Assessment. I would like to introduce Mr. Al Reyes, who is a Fellow at OTA who has been working with me.

I get the job today of talking about the cold numbers. I think we've had a lot of people talk about the more personal costs of disability. When you ask OTA to talk about costs, I think you want to have a broad sense laid out. When we talk about costs of disability, we should understand that personal costs are the first thing. We have distinguished costs and expenditures.

Simply put, for numbers, there are 33 million Americans who have some sort of disability; 14 million of them who have big-time problems. When we think about these disabled individuals, we should think about the fact that these people are excluded from experiences in a lot of ways. Other individuals have testified the personal cost people; the numbers confirm these costs.

These personal costs are demonstrated by measures of family disruption and family stress. The most dramatic statistics show that 40 to 70 percent of these people are out of work, unemployed. They are twice as likely to be in low income groups. Two-thirds of these unemployed people are individuals who want to be working. We have a big chunk of people out there who are disabled and want to be working, but are not in the system.

This brings out a point that should be emphasized; when we talk about disability, we understand that there are physical impairments, some impairments are going to keep some people out of work, no matter what. But there is also a social component to disability.

At OTA, we have distinguished these components by talking about the physical impairment, the disability, which is the fact that you can't get around; and then the handicap, which we distinguish as being something that results in a sort of social circumstance.

I think the nicest way to explain this is to say that if you have somebody who is paralyzed, that's a physical impairment. It can be a mobility-related disorder which requires a wheelchair. But it's only a handicap if you have a society that doesn't make a commitment to accessible buildings or curb cuts; then they can't get anywhere.

If you keep that distinction in mind, you see that there is a social element to what happens and what keeps people out of the work force. That social element is something that we can manipulate by altering social circumstances. That is a social element that can allow us to bring people back into participation.

The question is, how many of these people can we bring back in and what are we going to gain by doing it? I think in terms of actual costs, the numbers that we get show us that this is a big issue.

First of all, if you review expenditures that we lay out as a Government and as a society for disabled people, we are paying a lot of money. We are now paying out of the Federal budget, on the big five programs that deal with disability, $60 billion. No matter how I look at that, that's a lot of money.

Senator **Harkin**. Back up a minute. I have to understand that. Where did you get that figure?

Dr. **Boardman**. We put together Medicare, Medicaid, only for disabled people in both of those programs; Social Security, SSI and SSDI, again, only for disabled people; Veterans programs, only for disabled people; and then the Department of Education programs, (i.e. vocational rehabilitation). It should be on Page 10 of the written testimony.

Senator **Harkin**. You go right ahead. I have some questions I will ask later.

Dr. **Boardman**. Yes. It's a big number. The comparable number we found in the Federal budget was that we spend $75 billion on all of our personnel costs for the military.

The problem is that what we spend on disability is sprayed over a lot of programs. It includes health programs, and we're not going to change that cost. It also includes income maintenance programs, and those costs are changeable, because we can get some people back to work if we change social circumstances of disability. But it's a lot of money, and I think we ignore it only because it's spent over several different agencies. The total national expenditures on disability probably would be twice that, $120 billion, this includes state programs, and private disability programs,

Reviewing these expenditures, it is important to keep in mind that we are spending some of this money for income maintenance for disabled individuals who would like to reenter the work force. These individuals need support services to reenter the workforce but if they did reenter the workforce the income maintenance expenditures would be saved. The next question is, what component of these people need assistive technology?

The first thing you want to think about is that assistive technology is only a component of rehabilitation. We couldn't get you direct numbers on what assistive technology does of rehabilitation per patient, for cost-effectiveness. But rehabilitation is considered to be extremely cost-effective. There are various ways of measuring rehabilitation costs and effects; But the numbers indicate $3 to $11 are returned for every dollar spent on rehabilitation. These numbers vary depending on how disabled the person is.

We have given you estimates of what role technology could play in that rehabilitation. We estimate that technology would play a role in 20 to 40 percent of cases. These numbers draw on estimates from employers and from individuals. Those people are saying that they can't get people into the work force because they don't have technology in a range of 20 to 40 percent of cases.

A final point is that when we've talked about technology, assistive technology programs, and how you would bring people into the system, I think it has to be underscored that you can't just say, "We're going to give somebody a gadget and they're going to be fine."

OTA thinks about technology as a knowledge system it is important for everyone to understand that. You can give someone a gadget, and it's useless if they don't know how to use it; if they don't have the training; if they don't have the maintenance; if they don't have the upgrades; if they don't have a whole service delivery system that supports it. When you think about assistive technology, you have to focus on the delivery of assistive technology, and it has to be integrated into a system.

We all know of examples of useless pieces of equipment that we've bought ourselves. You can have my exercise cycle from the garage if you want it; it's not being used. You don't want to buy useless pieces of equipment; you want to buy a system that allows people to know, to understand, and to use and to come back into the social framework where they want to be.

I did that rather quickly. Did you have any focus questions?

Senator HARKIN. I'm going to have some that I will ask after the other panelists are finished.

[The prepared statement of Dr. Boardman follows:]

TESTIMONY OF BARBARA BOARDMAN, MD, MPH
OFFICE OF TECHNOLOGY ASSESSMENT
U.S.CONGRESS
BEFORE THE SENATE COMMITTEE ON LABOR HUMAN RESOURCES
SUBCOMMITTEE ON THE HANDICAPPED

Technology and Disabled People

May 20, 1988

I am Barbara Boardman, physician and senior analyst in the Health Program of the Office of Technology Assessment (OTA). I am here today to comment on the use of technology by disabled people.

Definitions and Demographics

The first steps in assessment are defining the problem and measuring the need. In the 1982 report Handicapped People and Technology, the Office of Technology discussed the difficulties that arise in determining the definitions and demographics that are the foundation of disability policy. In that report, OTA stated "there is no dependable count of the total number of disabled or handicapped persons. Indeed, such a measure is ambiguous and conceptually unsound." The definition that is used for disability will determine the numbers that are measured.

Definitions of disability fall into two categories: measures that focus on loss of function, and measures that focus on prevalence of chronic health conditions. Some studies combine both types of measures. There have been discussions about the philosophical and policy implications of using the different types of measures.

OTA has distinguished three terms: 1) "impairment"--a physiologic, anatomic, or mental loss or abnormality; 2) "disability"--a limitation of a generic human function resulting from impairment; and 3) "handicap"--a limitation that results in a socially, environmentally, or personally specified context (OTA 1982, p 20). For example, the individual who is paralyzed (an impairment) may have a mobility-related disability, which becomes a handicap when buildings are inaccessible to wheelchairs. Studies that use definitions of disability based on chronic health measures focus on impairments and disabilities. Studies that use functional measures as a definition are more likely to focus on handicapping conditions.

Chronic health measures and functional measures used can be tailored with varying tightness of fit, resulting in larger or smaller counts. For example, a functionally-focused definition could define disability as a condition that prevents or limits an individual's ability to work (Harris et al, 1986). A smaller number would be found by counting those who are prevented from working as compared to counting those with any work limitations. A functional count of those who are limited in "activities of daily living," such as eating and dressing, would provide a smaller count of more severely disabled individuals.

For this discussion, we drew on several large surveys of the disabled population. Distinctive features of the data sets should be noted. Census data on disability use a broad functionally-related definition of disability. The data on disability from the National Health Interview Survey (NHIS) evaluate a non-institutionalized disabled population; the definition of disability involves a combination of functional and chronic health measures. The International Center for the Disabled (ICD) survey of disabled Americans done by Louis Harris and associates in 1985 also uses a combination definition of disability in a study of 1,000 disabled, non-institutionalized individuals aged 16 years or more.

The Size of the Disabled Population

Because of the imprecise nature of what is being counted, measures of the size of the disabled population can vary considerably. In 1982 OTA found estimates of the total disabled American population that ranged from 15 to 45 million (OTA 1982 p 21). Census publications list 37 million Americans (about 20%) as having "some disability." Of these 13.5 million or about 7.2% had a severe disability (Disability, Functional Limitation and Health Insurance Coverage 1984/5, U.S. Bureau of the Census, 1986).

The Harris survey screened 12,500 households and found a prevalence of disability of 15 percent (an estimated 27 million Americans) in the population aged 16 years and over (Harris, 1986). The National Health Interview survey found a prevalence rate of 14.1 percent; this rate is similar to the Harris data. The NHIS data cover a non-institutionalized population of all ages. It yielded a national total of 32.5 million persons of all ages reporting some activity level limitation due to chronic health conditions. In this data set, the amount or kind of major activity was limited in 5.9% of the population, the ability to perform major activities was limited in 3.8% of the population.

While there is debate about the exact numbers, there is a general consensus about the demographic patterns that describe the disabled population. Overall, the disabled population is disproportionately elderly, out of work, low income, and undereducated.

Age Distribution

The prevalence rate of disability in the population generally rises sharply with age (NHIS p 10). This occurs across all degrees of severity of disability. The simplest explanation for this phenomenon is that the longer 2an individual lives, the greater the exposure to disease or accidental injury. In the Harris (1986) data, the age of onset of limitation distributed regularly across the age groups (48% had the onset of the limitation during childhood, 26% had the onset in young adulthood, 29% had onset in middle age and 36% had onset after age 55). The prevalence rate of multiple impairments also increases with age.

Berkowitz (Disabled Policy, 1988) notes that the increase in prevalence of disability with age is not simply a physiologic fact. Institutional factors also come into play. The impaired individual is more likely to leave the work force if he or she is older. Early retirement may be socially tolerable at 55 years of age; it is not as culturally acceptable at age 28.

Participation in the Workforce

Census data show that disabled workers are disproportionately out of the workforce.

Table 1

Percent of Population Unemployed or Not In Workforce, Aged 16-64

Gender	Able	Disabled
Male	19.7%	71.3%
Females	92.0%	43.5%

Source: Current Population Survey, U.S. Bureau of the Census

The Harris data confirm this pattern; 66% of disabled respondents aged 16 to 64 were not working. If those who were active in activities not related to employment (i.e., retired, keeping house, students or volunteers) are excluded, the number drops to 40% of disabled individuals that are not working.

These numbers should be viewed in context. Inability to work is a major part of the definition of disability. One would expect high rates. The question that follows is: what percentage of these disabled individuals would reenter the workforce if they could? Harris (1986) survey data indicate that 66 percent of the nonworking disabled persons under age 65 said they wanted to work

Education

Employment rates for disabled individuals are much higher for those who have more education. Sixty-seven per cent of disabled individuals with 16 or more years of education are employed as compared to 17.6 percent of those with less that 8 years of schooling (Bowe, F., Disabled Adults in America: a Statistical Report drawn from 1982 Census Bureau Data, President's Committee on Employment of the Handicapped, Government Printing Office, Washington DC).
Unfortunately, it is also true that education level is inversely associated with the prevalence of disability (38% of those in the Census sample with less than a high school education reported some limitation in activity; for college

graduates the percentage drops to 10.5). Persons with 8 years or less of education had the highest risk of being unable to perform a major activity (13.6%); while those with 16 or more years of education had the lowest risk (1.9%).

There is a caveat that accompanies these data. The disabled population is older than the able population. It may be that some of the education effects demonstrated are spurious effects that appear because older segments of the population had less access to education. In spite of this caveat, the numbers are strongly suggestive of the effects of social interactions in disability statistics. The physically impaired individual who has a college education is much less likely to have his or her disability become a socially-defined handicap in terms of exclusion from employment.

Income

Data indicate that disabled individuals are disproportionately represented in low income groups. In the Harris (1986) survey, 50percent of disabled persons reported household incomes of less than $15,000 for 1984. Among able Americans, only 25 percent had household incomes in this bracket. In the same survey 32% of all disabled persons over 65 years of age reported household incomes of less than $7,500 per year. NHIS data indicate that income decreases as the disability becomes more severe (41.5% of those unable to perform a major activity had incomes of less than $10,000 as compared to 16.6%

of the able population). Harris data indicate that disabled individuals who are employed are financially better off; they are more than twice as likely to have incomes above $25,000 as are the nonworking disabled.

The data that indicate income is low for disabled individuals are not surprising. The intertwined factors of disability, low educational attainment, and physical disability would be likely to render an individual particularly vulnerable. We again note that social factors interact with physical impairments to create handicapping conditions.

Costs of Disability

Federal Government Expenditures

Cursory review of the demographics of disability indicates that the disabled individual often bears a substantial personal cost for his or her impairment. Social programs are intended to buffer these costs. The effects of disability can be classified in three general categories:

1) Income maintenance: These programs include government programs such as Supplemental Security Income(SSI) and Social Security Disability Insurance (SSDI) and private disability insurance.
2) Health insurance: These programs include Medicare and Medicaid.

3) Support services: These programs include vocational rehabilitation and various educational support programs for disabled children.

It should be noted that programs may combine elements of the three classifications. Workers compensation programs and veterans benefit programs have health insurance and income maintenance components. It should also be noted that health insurance subsidies can function as substantial income supports for individuals with costly health care bills.

Tracking the programs that serve disabled people is a difficult task. In 1982, OTA found 44 Federal government programs providing various services to disabled individuals. Federal budget items are spread over various departments and various agencies. The major programs are those noted above (Medicare, Medicaid, SSI, SSDI, Vocational Rehabilitation and special education and veterans programs). Services for disabled individuals in these programs account for $60 billion in the Federal budget. Uncounted in this figure are programs for disabled individuals located elsewhere in the Federal government. Such programs exist within the departments of Labor, Housing and Urban Development, Transportation, and Treasury as well as various other agencies, including the General Services Administration, the Small Business Administration, and the Library of Congress.

Table 2

Amounts Spent by the U.S. Government on Major Programs for Income Compensation and Medical Care for Disabled People (Includes Medicaid, Medicare, Department of Education, Social Security, and the Veterans Administration):

Program	Population	Amount Spent
Medicaid[1] - FY 1987 (figures not final)[2]		
Disabled beneficiaries (with total and permanent disabilities):	3,299,556	$16,512,626,112
Medicare[3] - FY 1987 (estimated figures)		
People with disabilities or ESRD:	3,000,000	$9,069,000,000
Department of Education - FY 1987		
Rehabilitation Services Administration:	917,482	$1,270,000,000
Special Education[4]:	4,200,000	$1,338,000,000
Social Security[5] - as of Sept. 30, 1987		
Disabled workers receiving Disability Insurance (Title 2):	2,800,000[6]	$18,100,000,000 +$2,500,000,000 to family members
Blind and disabled people receiving Supplemental Security Income (Title 16):	2,900,000[6]	$7,627,000,000
Veterans Administration[7] - as of Mar. 31, 1988		
Veterans receiving disability compensation or pensions:	2,820,614	$11,038,886,412[8]
TOTAL AMOUNT SPENT:		$59,868,000,000

Notes and sources listed in appendix 1.

Expenditures at the State Level and in the Private Sector

In addition to Federal expenditures, there are state level expenditures and private sector expenditures. Review of the costs of these programs indicates that they add a significant amount to national disability expenditures. The U.S. Chamber of Commerce placed workers compensation costs at $16.1 billion for 1982; this figure included $4.8 billion for medical costs and $11.3 billion for indemnity (Chamber of Commerce, 1985). Private disability income protection benefits paid by insurance companies in 1981 were another $5.2 Billion (Snook and Webster, 1987).

The business literature focuses on the costs of disability to the corporation. This literature often lumps the costs of short term (less than two years) and long term disability. The Washington Business Group reports that $7 Billion is spent on sick leave annually. Of total payroll costs 2-4 percent goes for short term disability and another 1/2 to 1 percent goes for long term disability. Stating these costs in business terms, the business group writes, "a company with 1000 employees can expect to have 27 lost workday injuries a year; with a 4.5% profit margin, the company must realize $11.3 million in sales to offset these costs" (Carbine, Schwartz, 1987).

Total National Expenditures for Disability

In short disability expenditures are scattered over various fields, including a range of Federal, state and private programs. This scattering of the data renders an accurate assessment of the total expenditure difficult and uncertain. Dispersion of data functions to hide the total figure and obscure it from national attention. Berkowitz has calculated disability expenditures at $120 billion (Berkowitz, 1985). While these numbers are not 1987 totals, they are consistent with our review and suggest a plausible range for disability expenditure.

Other Costs of Disability

The figures we have reviewed are best described as expenditures for disability; they represent disbursements of funds for health care expenditures for income maintenance and for rehabilitation and support services. Such expenditures should not be considered the full measure of the costs of disability. Costs must be viewed more widely. The loss of production and participation by disabled citizens is a cost we are not able to put a dollar value on.

Gross review of the data on workforce participation and income distribution demonstrates that the major costs of disability are born by the disabled individuals themselves. The costs include not only lost income and work participation. The data demonstrate that disabled individuals are more likely to be excluded from participation in social and community activities. Harris data also indicate that being disabled means having less of a social and community life. Disabled individuals attend restaurants, movies, theaters, sports events, and churches or synagogues less frequently. They socialize with family and friends less frequently. Able individuals reported active involvement in religious, volunteer or recreation groups at a rate of 60 per cent; for the disabled population this rate was only 36 per cent.

In most of our discussion of costs we have focused on the costs for the adult disabled population. Statistics also indicate that disabled children and their families bear significant costs of disability. National Institute for Disability and Rehabilitation Research (NIDRR) data show that the income earned by families of disabled children is disproportionately low. The health care burden is higher for these families. It is also plausible that social stresses on these families are higher.

Table 3

Measures of Family Stress:
Comparisons of Families With and Without Disabled Children

Family Stress	Family with disabled child	Family with no disabled children
Families with income <$15,000	44.0%	34.5%
percent of famililtes reporting inpatient hospitalization in the past year		
-child under 5 years	52.6%	19.3%
-child 6-17 years	66.6%	40.2%
percentage families with Parents divorced or separated	11.9%	19.0%

Source: Summary of Data on Handicapped Children and Youth, Human Services Research Institute, prepared for NIDRR, December 1985, US Government Printing Office.

In summary, the costs of disability are difficult, probably impossible, to fully quantify. The large expenditures for disability payments are best understood as a benefit system that attempts to buffer the costs of that system to individuals and their families.

Rationalizing Policies for Disability Services

Rational disability policy should be built on a solid appreciation of the diverse nature of the disability system. The disability system serves individuals with different needs and should provide those individuals with different services. As mentioned above, three general categories of services are provided. A clearer understanding of each of these categories may permit a more rational focus for policy analysis.

1) Health care insurance subsidies are one of the major services this population needs and uses. It is implicit in the definition of disability that health care costs for this group will be high. Income and employment data also imply that these individuals are less able to depend on private insurance.

2. Income maintenance services are intended to support those who cannot provide adequately for themselves. It should be underscored that for a percentage of the population, physical disabilities are so overwhelming that active participation in the economic sector, even with substantial support services, is an unrealistic expectation. Data indicate that another segment of the disabled population is isolated from the productive sector as a result of the interaction of social factors and physical disability. For example, a 25-year-old quadriplegic with an eighth grade education is less employable than a college graduate with the same physical impairment. Income maintenance subsidies to disabled individuals in this socially defined segment expand and contract.

3. Support service programs, such as vocational rehabilitation for adults and specially designed education programs for children,arise from policies that are intended to alter the social circumstances that make physical impairments become handicapping conditions. Such programs can operate by enforcing change at the societal level (e.g. civil rights guarantees for disabled individuals, or programs for removal of architectural and transportation barriers). Other programs operate by providing services to the disabled individual. Individually focused programs can provide supports for education and training, attendant care, or assistive technology services.

Analysis of the circumstances of disability and of the nature of disability expenditures implies that there are two complementary strategies for reduction of the societal costs of disability. The first of these is to prevent physical impairments from occurring. The second is to reduce the social barriers that make impairments into handicaps. The issues of prevention are important to a full disability strategy, but they will not be discussed further in this paper.

Policies that manipulate the social circumstances of disability will not eliminate the costs of disability; they can only function to maximize what individuals can do within the physical limitations of their impairments and minimize the costs of disability. Tactics designed to provide assistive technology to disabled individuals can play a part in a strategy that attacks the social barriers that define handicapping conditions. To be effective such tactics must be integrated into a full rehabilitation strategy.

Assistive Technology and Rehabilitation Strategies

The role that assistive technology can play in a rehabilitation strategy is inherent in the definition given to assistive technology. Technology has been defined as "the application of an organized body of knowledge to practical purposes." (OTA 82 p. 51) This definition encompasses not only physical objects, such as communication devices, but also processes such as vocational rehabilitation and reimbursement systems. It should be underscored that it is not the gadget that defines the usefulness of a technology; it is the knowledge of the user that converts the gadget to a useful tool.

Technologies designed for, and used by, individuals with the intent of eliminating, ameliorating or compensating for functional limitations are considered "assistive technologies" for the purposes of this analysis. It should be noted that we have focused on personal assistive devices, but the definition of technology clearly implies that such devices must be considered as only a part of the foundation we lay when we build a system of support for disabled individuals.

Factors Effecting Availability of Assistive Technology

Barriers to implementation were found to be related to the four factors that bring technology to the user. These factors are:

1. DEVELOPMENT of the device or process. New ideas are the first and most obvious step in creating new assistive technologies. Full development of an idea involves applied research, testing, and development of the production process.

2. DISSEMINATION of information about the devices or process. Consumers and the care providers who work with them can use equipment only if they are aware of its existence and how to get it.

3. DELIVERY of the device or process. There must be a system that delivers the product to the consumer, trains the consumer in the method of appropriate use, and maintains the product in working order. The delivery system for assistive technology involves consumers and several levels of professionals who evaluate the consumers need, prescribe devices or systems, train consumers in methods use, and maintain equipment in working order.

4. DOLLARS to pay for the device or process. Every element of the system has a cost; the availability of funding to cover the costs of the device and of the costs of development, dissemination and delivery will be the deciding factor in what assistive technology a disabled person actually receives. Simply put, dollars drive development, dissemination and delivery.

The most important barriers to the availability of assistive technology are the unpredictable and inadequate funding of such services and the uncoordinated and incomplete structure of the delivery system. The incomplete nature of the information dissemination system was also found to hinder the availability of such services. These issues are discussed more extensively in the appended testimony to the House Committee on Education and Labor Select Committee on Education presented May 10, 1988. It should be underscored that the problems with availability of assistive technology are the inevitable result of the failure to integrate assistive technology policies into a unified rehabilitation strategy.

Lowering the Costs of Disability

For impaired inividuals whose disability can not be changed adequately, we can alter the social circumstances in which they function. By doing so, we may alter certain sectors of disability expenditure. As has been previously stated, the expenditures for disability fall into three categories, health care expenditures, income maintenance and supportive services. The health care costs for this population are not likely to respond significantly to manipulation of the social circumstances of disability because these costs are a result of the physical impairments they suffer. The income maintenance needs and costs of those who have very severe physical disabilities are also unlikely to change.

The most plausible focus for cost reduction is the manipulation of social circumstances that hinder participation for those who could have a higher level of participation. This suggests that programs focused on rehabilitation, independent living and support services are possible methods for reducing expenditures. If such programs are designed to work with, not for, the disabled individual, they may also decrease the personal costs of disability.

There are data that measure dollars saved per rehabilitation dollar spent. A number of problems make it difficult to use this data in a standardized manner. The costs of rehabilitation vary with the type of impairment and degree of impairment. Costs of rehabilitation of one population cannot necessarily be projected to other populations. Outcome measures are unclear. Because costs and benefits are charged to several different systems, analysts must make clear what benefits are being measured. Benefits may be measured for business, the government, the individual or society.

Various studies present data on the effectiveness of rehabilitation. Data from the Rehabilitation Services Administration ("Economic gains through vocational rehabilitation" Rehabilitation Services Administration, Division of Program Administration, Basic State Grants Branch, July 1982) demonstrate estimated lifetime earning improvements of $8.00 to $14.60 for every $1.00 spent on rehabilitation. The state of Michigan compared the costs of state workers' compensation benefits with rehabilitation expenditures and found that rehabilitation services were cost effective for the agency (Lanham, 1988).

Private sector studies also suggest that rehabilitation may be cost effective. A survey of companies with rehabilitation programs by the Health Insurance Association of America (HIAA) indicated that of 47 of 55 companies that tracked the costs of rehabilitation programs reported measurable savings. For the 17 companies that provided data, a savings of $11.00 for every $1.00 spent on rehabilitation was reported (HIAA, 1987). In a study that focused on a particular disability, back pain, Maglioozi and LeClair found corporate savings of $3.50 for every $1.00 spent on rehabilitation. This number includes the cost of services to those who failed their rehabilitation (Magliozzi, and Leclair, 1981).

While these numbers suggest that rehabilitation may be cost effective, a caveat is offered. Most of these studies show that rehabilitation was effective with a particular sub-population. It is reasonable to conclude that for particular segments of the population, rehabilitation is extremely cost effective. This cost effectiveness has been demonstrated in government and private sector settings.

Data that suggest the effectiveness of rehabilitation for the general disabled public are not available. The percentage of the disabled population which could be rehabilitated would vary with age, with degree of disability and with the nature of the job market. The most optimistic projection of a rehabilitation rate could be drawn from the Harris data (1986). Of disabled persons aged 16-64 who were not working, 66 percent said they wanted to work. Calculating from the Harris data we project at least 26.4 percent of the non-working disabled would be interested in rehabilitation. In the Magliozzi and LeClair back pain study 38 percent (78 cases) were considered productive at the end of the study; 13.7 percent (28 Cases) had returned to work.

The Effect of Assistive Technology on Rehabilitation

To project the effect of assistive technology on rehabilitation rates, it is necessary to know the degree to which the absence of assistive technology prevents rehabilitation from taking place. The Harris (1986) survey asked disabled individuals aged 16-64 years the reasons why they were not working. Twenty-three percent responded that they needed special equipment or devices to do work, talk or hear others, or get around at work. In answer to the same question, 28 percent responded that they couldn't get convenient, affordable accessible transportation. Of those disabled individuals who were employed, 35 percent stated that their employer had made some accommodation to their disability.

Projections of the possible effects of assistive technology should also incorporate the employer's assessment of the need for technology. Harris (1987) data from a survey of employers of disabled employees indicate that between 18 percent and 65 per cent of employers have made adaptations in the workplace. Small employers (10-49 employees) were less likely to make adaptions. Of those who made workplace adaptations for disabled employees, 50 percent purchased special equipment. Employers who had not hired disabled employees said that in 38% of cases a lack of special equipment was an important reason for not hiring and training these people. (Louis Harris and Associates 1986).

It is important to note that assistive technology is not independent of the rehabilitation system. Harris (1987) data suggest that it is plausible that the availability of technology would play a role in rehabilitation in 20 to 30 percent of cases. The same data survey suggest that health factors prevent employment in 78 percent of cases. Social barriers, such employer prejudice, lack of skills or education, and lack of available jobs, are cited in 38 percent to 47 percent of cases. Assistive technology will not remove social or health barriers to participation. In the absence of a coordinated rehabilitation system, devices provided to disabled individuals will be underutilized.

Integration of assistive technology into the rehabilitation system will require that the current delivery system be rationalized. There is a general consensus that the current delivery and funding system is difficult to navigate. Interestingly, there is a fair degree of consensus (Berkowitz, 1987, Vanderheiden, unpublished, Rahl, unpublished) that a more rational system is possible. Various states, (New York, Florida, Minnesota, Pennsylvania, Wisconsin) have been working on improved models of disability technology delivery. While there is not uniform agreement on the model of such a delivery system there are principles that emerge from the review as useful focal points for discussion:

1. The current lack of coordination in funding and the resulting balkenization of care delivery confuses and frustrates all who use the system. The system is segregated by age. Many people believe that it is likely that inequities of coverage by geographic, ethnic, racial, linguistic, and disability group also occur.

2. It is possible to conceptualize a more rational system. Such a system would have to be woven into an integrated disability policy. Segregation of assistive technology policy from other aspects of disability policy, such as independent living, rehabilitation, income maintenance, and health care would only further fragment care. This does not imply that all disabled individuals need to receive identical services. Rather it implies that these services should be matched to the needs of the individual, not to the funding system.

3. A more rational system would require a coordinated information system. Such a system would have to:

be a unified information network,
be predictably and continuously funded,
incorporate consumer feedback,
involve information exchanges in several formats, and
be accessible to the full range of users.

4. A more rational delivery system for assistive technology would require the active interaction of consumers and professionals who are willing to work with, not for, the disabled. Various existing professions (e.g. rehabilitation physicians, occupational and physical therapists, nurses, special education teachers, rehabilitation counselors, social workers) and emerging professionals, such as rehabilitation engineers, will have to find a place in the system. Training programs for such professionals may need to be altered or expanded to fit the changing pattern of care delivery.

5. Rational delivery systems for assistive technology must address the issues of maintenance and upgrades. Maintenance and replacement of devices must be considered an implicit part of the cost of the device for the disabled individual who needs assistive technology. Support systems that ignore these costs will understate the costs of assistive technology

6. The issue of coordination of care between various disability support systems has not been adequately addressed. Accounting and ownership and leasing systems could be adjusted so that assistive technology could follow the user where appropriate.

7. Funding is the system that drives care delivery. Policies to rationalize the delivery of assistive technology will have to address the nature of the funding system both in the private and the public sector.

Appendix 1

Notes and Sources for Federal Budget Figures

NOTES

[1] Source: Leroy Roberts, Program Analyst, Office of Medicaid Estimates and Statistics, Office of the Actuary, Health Care Financing Administration, U.S. Department of Health and Human Services

[2] Figures not final, some state totals not included

[3] Source: Dave Wood, Bureau of Data Management and Strategy, Health Care Financing Administration, U.S. Department of Health and Human Services

[4] IBID Dave Wood, OTA calculated totals.

[5] Don Barrett, Clearing House on the Handicapped, Department of Education.

[6] Social Security Administration, public information service, SSA.

[7] 18-20% of these populations are eligible fo social security under both title 2 and title 16.

[8] Source: Mike Wells, the Veterans Administration

[9] These monthly figures are as given; annual rates were calculated by multiplication.

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Senator HARKIN. Thank you very much.

Steve White, Director of the Reimbursement Policy Division of the American Speech-Language-Hearing Association.

Steve, welcome to the subcommittee, and please proceed.

Dr. WHITE. Thank you very much, Mr. Chairman. We really appreciate your leadership in this whole area of assistive technology, and we completely support of your work.

We feel like a hard luck baseball team: We can get to the stadium; we can play as hard as possible, but we can't seem to win very often. There are people out there with disabilities who can get the technology, but when it comes to third-party payment for that technology, it's a real difficult time winning the game—and it seems to be almost a game.

Some of the reasons for those problems, especially as they relate to health insurance programs, are that they are not medical. Assistive technology is not surgical, and it isn't medicine. Oftentimes, as you have heard during these past 2 days, the services are supplied some place other than in a hospital, the major provider of health care. No one seems to want to pay for those services. Everyone seems to want to be, at best, the payor of last resort.

The Federal and state systems that exist today are a maze. They are either children or adult-oriented rather than both. They have eligibility requirements, that is, means testing. It's very difficult for the consumer and for the professional to solve this maze when it comes to getting payment for the device and services related to the device.

We can talk about programs, Federal programs, Medicare; the Federal and state program of Medicaid; we can talk about private insurance programs, and on the other side, we can talk about special education, vocational rehabilitation. Then there is indirect funding, as you have talked about earlier, regarding income taxes and Supplemental Security Income, and other programs like the Older Americans Act, which are involved with assistive technology support for funding.

I would like to start talking about Medicare because Medicare will not pay for assistive technology, as we've had discussed during the last two days. Our area of concern is communication devices. Medicare tells us that communication devices and other assistive technology are classified as convenience items, or personal luxury items. We know different, but the Health Care Financing Administration is not willing to admit it.

Other devices like hearing aids, are specifically excluded by statute, from coverage under the Medicare program. Today, Medicare will pay for costly cochlear implant surgery and the device, but it will not pay for hearing aids. It will pay for an artificial larynx, because the larynx has actually been removed, but it will not pay for an augmentative communication device.

Medicaid—with services and devices, all comes down to an optional benefit for the states. Some states pay for the device and the services, but it's not uniform. As a matter of fact, in Iowa, there is now payment for augmentative communication devices, but it took a court case to get Iowa to move on it. Now there are regulations in Iowa for coverage of augmentative communication devices.

Private insurance is another area that has problems. With children, many of the problems that cause a need for assistive technology are congenital in nature. Private insurance tends to pay for health problems that are related to accidents and illnesses, and so they do not pay for services or devices related to developmental disorders. Again, it's more rehabilitative than medical or social, as Dr. Boardman pointed out, so private insurers look the other way as well. However, appeals through private insurance companies, and especially through self-insured companies, have found support for assistive technology.

Special education and related services tend to be a local problem. P.L. 94-142 addresses assistive technology, but people at the local level have trouble recommending it because local education agencies say funds aren't available, so they don't recommend it on the IEP. Vocational rehabilitation also emphasizes assistive technology, but the funding doesn't seem to be there.

SSI is also mentioned in our testimony. Here, there's a disincentive for recipients to save so they can pay for assistive technology. It they save, they will not longer qualify for SSI.

For income taxes, there are problems discussed in our testimony. One is that the medical deduction has increased for all of us and in order to qualify for that medical deduction, a great deal of money has to be spent. Now, in the House of Representatives, there are discussions regarding legislation that may lead to additional paperwork so that not-for-profit programs, that provide these services, provide the technology, and provide the type of research that is necessary, will have a paperwork burden in order to show that the services and devices they are providing are related to their not-for-profit mission.

Our recommendations are that Medicare and Medicaid programs be amended so that prosthetics include assistive technology. We believe that the Education of the Handicapped Act, the Developmental Disabilities Act, and the Rehab Act also require amendments to clarify the role of assistive technology.

We believe that the Supplemental Security Income Program needs to be amended, too, so that assets can be accumulated toward the purchase of assistive technology. And last, that the Internal Revenue Code provide tax credits, tax deductions, accelerated writeoffs, and other incentives that were discussed here earlier.

We also believe that there should be a National Assistive Technology Funding Commission to study the issues related to funding for assistive technology. The specific recommendations for that commission are included in our written testimony.

Thank you very much, Mr. Chairman, and we look forward to working with you and your staff.

[The prepared statement of Dr. White follows:]

AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

Statement on

FUNDING AND REIMBURSEMENT
FOR ASSISTIVE TECHNOLOGY

Before the

SUBCOMMITTEE ON THE HANDICAPPED

COMMITTEE ON LABOR AND HUMAN RESOURCES

U.S. SENATE

Presented by

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May 20, 1988

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STATEMENT OF THE AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

Mr. Chairman and members of the Subcommittee on the Handicapped:

The American Speech-Language-Hearing Association (ASHA), representing more than 56,000 speech-language pathologists and audiologists nationwide, is pleased to have this opportunity to provide information on issues concerning reimbursement for assistive technology and related services. As part of this statement we will discuss (1) general problems related to reimbursement, (2) problems related to specific public and private reimbursement programs, and (3) possible solutions to enhance reimbursement.

In discussing "assistive technology" it is necessary to indicate how the term is used. For the purposes of this statement, assistive technology includes related services and is defined as including any identification, assessment, training and case management activities needed to support the use of assistive technology. Moreover, payment for assistive technology includes:

(1) costs necessary to purchase the technology regardless of sophistication;
(2) devices and equipment needed by an individual with disabilities; and
(3) necessary maintenance, repair and replacement costs.

When discussing issues related to reimbursement for assistive technology, it is important to consider not only the costs associated with purchase of the aid or device itself, but also the costs associated with assessment, training, case management and maintenance, and repair and replacement of the aids or devices.

GENERAL PROBLEMS

During the past decade there have been dramatic advances in the development of assistive technology which can substantially improve the quality of life for individuals with disabilities. But unfortunately the reimbursement systems available for assistive technology have not kept pace with the technology. In fact, many funding sources have clearly imposed limitations by placing caps on reimbursement or by requiring they be the "payor-of-last-resort."

I submit, Mr. Chairman, that the major problem related to reimbursement of assistive technology is that no one wants to take responsibility for paying for such technology. As a result, millions of Americans with disabilities do not have access to the technology that would allow them to obtain gainful employment, become self-sufficient citizens, or enhance their quality of life.

Federal and state service programs, public and private payors and proposed legislation related to assistive technology can require extensive planning to ensure that individuals who need assistive technology are identified, assessed and have the resources for appropriate assistive technology. However, if no one is willing to pay for the necessary individual assistive aids and devices, the entire system becomes ineffective in terms of the desired outcome--a productive, independent citizen who also happens to be disabled.

Individuals with disabilities who need assistive technology face a number of problems in obtaining necessary technology and services. For example, there is no single, identifiable source one can use to obtain the necessary identification, assessment, placement, training and follow-up services, and financing of the assistive technology. Federal reimbursement programs can best be described as an "amazing maze." Although there are many federal resources, they are not coordinated in any way nor do they have consistent eligibility requirements. Some programs require a needs test; others do not. Some are available to adults, others only to children. Some payors require that individuals meet eligibility standards for that program. Other programs for children and adults which complement each other are not consistent in funding assistive technology. Even if an individual with disabilities does qualify for the third party payor, there may be an arbitrary denial of funding for assistive technology or there may not be enough funds to pay for needed assistive technology.

Most private insurance plans do not explicitly include or exclude coverage of assistive technology in their benefits. As a result, claims for such technology are usually denied. Clients who are familiar with the system or who have knowledgeable professionals guiding them, appeal the initial denial and eventually obtain payment for the needed device or system. However, once again the consumer must overcome "red tape" and devote extensive resources toward obtaining needed services.

Clearly, the lack of an identifiable and coordinated reimbursement program for obtaining assistive technology services, aids and devices is a problem for individuals who need such help. It is unrealistic to expect that either the individual who needs technology or the professional who is concerned about providing quality services is going to have the knowledge or time to solve the maze necessary for obtaining funding for assistive technology. Action must be taken to clarify and simplify the financing system and to ensure that someone in the public or private sector is the payor-of-first-resort, not the last.

SPECIFIC PROBLEMS: EXISTING FUNDING PROGRAMS

There are a number of public and private sector programs that do, could, or should pay for assistive technology. What follows is a discussion of some of those programs and the problems associated with obtaining funding for assistive technology.

Medicare

Part B of the Medicare program is a medical insurance program that includes coverage for rent or purchase of durable medical equipment (DME). Once an allowable charge is determined for a given piece of equipment, Medicare pays 80% of that sum with the remainder paid by the beneficiary or other third-party.

Durable medical equipment is defined as "equipment which (a) can withstand repeated use; (b) is primarily and customarily used to serve a medical purpose; (c) generally is not useful to a person in the absence of an illness or injury; and (d) is appropriate for use in the home." To obtain reimbursement for DME under Medicare Part B, all of the above must be met.

Medicare will also pay for a prosthetic device (other than dental) when it is a replacement of all or part of an internal body organ, or a replacement of all or part of the function of a permanently inoperative or malfunctioning internal body organ. Medicare also provides coverage for services related to replacement or repair of the device.

Under the Health Care Financing Administration's (HCFA) screening list published in the Medicare Carriers Manual, most assistive technology related to aids and devices that are considered "educational," "environmental controls," "hygienic," "self-help" or "convenience/comfort" items. Because the descriptions eliminate the item from qualifying under the requirements described above, payment is denied.

Among the types of durable medical equipment that are not covered are sensory and communication aids. Equipment such as augmentative communication systems that would enhance an individual's ability to participate in society are denied coverage because they are considered to be "convenience" items that are not medical in nature and do not replace an internal body organ. Hearing aids are specifically excluded by the Medicare statute.

However, there is an interesting inconsistency in Medicare policy as related to hearing aids. If a Medicare beneficiary needs a cochlear implant, reimbursement will be provided for the surgery to implant electrodes in the ear and for the device that provides the signal to improve hearing. However, if another Medicare beneficiary has usable residual hearing and would benefit from wearing a hearing aid, Medicare will deny coverage of the hearing aid. Ironically, a hearing aid and associated aural rehabilitation services would cost Medicare considerably less than a cochlear implant. However, purchasing hearing aids with Medicare funds is expressly prohibited by statute.

Medicare coverage for augmentative communication systems is treated similarly to hearing aids. Medicare will pay for an artificial larynx, but will deny payment for an augmentative communication system that would allow a non-speaking person with an intact but neurologically non-functioning larynx to communicate. But unlike hearing aids, there is no law prohibiting the purchase of augmentative communication systems. However, such systems are not paid for by Medicare because they do not fit into the Health Care Financing Administration (HCFA) coverage guidelines.

If there is really an interest in ensuring that assistive technology is available to individuals who can benefit from such technology, inequities in Medicare coverage must be resolved.

Medicaid

Title XIX of the Social Security Act established the Medicaid program to meet the basic health care needs of persons with low incomes. Title XIX requires each participating state to cover a core set of health care benefits including Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services. Provision of services in addition to the core services are at the option of the state. Funding for durable medical equipment (DME) is optional for the state.

In many states, Medicaid will pay for assistive technology, however it is limited to individuals under the age of 21 because under the EPSDT program the state is required to provide "health care, treatment, and other measures to correct or ameliorate any defects and chronic conditions discovered." As part of the treatment, states are required to provide "treatment for defects in vision and hearing, including eyeglasses and hearing aids." Thus, states provide reimbursement for such technology for recipients under the age of 21 but not for those in need of such technology over 21 years af age.

Because payment for DME, prosthetic devices and rehabilitation services is an optional benefit, many states do not provide coverage for assistive technology such as augmentative communication systems. However, some states such as Iowa, have established Medicaid rules that allow for coverage of augmentative communication systems. In part, the Iowa rule indicates that "augmentative communication systems will be provided for individuals unable to communicate through oral speech or manual sign language. Payment will be made for the most cost-effective item which meets the communication needs commensurate with the individual's cognitive and language abilities." Consumer and professional advocacy through appeals and the courts have prompted states to extend Medicaid coverage to augmentative communication devices.

Clearly, the Medicaid program provides an opportunity for obtaining reimbursement for assistive technology. However, with definitions that limit the kinds of equipment that can be funded and policies that allow states to select optional benefits it is obvious that changes must be made if the limited funds for this program are going to help all the categorically needy who need assistive technology.

Private Insurance

Private insurance reimbursement for assistive technology can be summed up in two words: "It depends." Payment for assistive technology by private insurance companies depends on the type of insurance policy, the language of the policy, the claims reviewers and their interpretations of the terms of the insurance policy, the latitude given to claims reviewers in making coverage decisions and their awareness of the needs and outcomes related to assistive technology.

There are four basic kinds of private programs that can be used to provide reimbursement for assistive technology. They are health insurance, disability insurance, worker's compensation and liability insurance. Clearly disability, worker's compensation and liability insurance have not been primary payors for assistive technology. If these policies pay for such technology, it has usually been the result of specific litigation related to an illness or injury requiring the use of assistive technology. However, health insurance can and has been used to reimburse for assistive technology.

Private sector health services are financed primarily by employer-sponsored plans including indemnity insurance, Blue Cross/Blue Shield service benefits, and health maintenance organizations (HMOs). The intent of health insurance is to insure against financial loss associated with illness and accidents. Health insurance can pay for assistive technology as long as its use is consistent with the insurer's obligation for maintaining or restoring a beneficiary's health. Payment for necessary assistive technology is closely tied to coverage for health care in a given setting--hospital, skilled nursing facility, or home health. If a policy covers the provision of health care services in these settings, it usually covers the cost of equipment necessary for effective treatment in these settings. Unfortunately, most health insurance policies are designed to cover medical services and not rehabilitation services. Therefore, claims for assistive technology that are more "rehabilitative" in nature than "acute" medical care are denied in most cases. Also, health insurance companies rely on physicians to determine the medical necessity of services and equipment and require physician prescription for any reimbursement request. To determine the need for and benefit of assistive technology, a rehabilitation professional may provide better information to make the necessary decision to reimburse for assistive technology.

Special Education and Related Services

The primary federal funding source for special education and related services is the Education of the Handicapped Act, specifically Part B--PL 94-142. This law requires that all handicapped children be provided a free appropriate public education that is based on an Individualized Education Program (IEP). The IEP is to include a description of all the programs and services a student needs to benefit from special education. Clearly, this could include assistive technology. However, most professionals are prohibited from including recommendations in the IEP that indicate a child needs assistive technology. This is due partly to concern about the cost of such technology and to Department of Education policy interpretations indicating that "individually prescribed devices are generally considered to be personal items, which are not required to be provided under Part B."

However, due process decisions rendered by hearing officers concerning provision and payment of assistive technology under PL 94-142 have held that local education agencies must provide equipment such as augmentative communication systems and personal computers for use at school and home if they are necessary for a child to receive a free appropriate public education.

Clearly, a child should not be denied a free appropriate public education because professionals are not allowed to include recommendations in the IEP for use of assistive technology that may benefit the child. Additionally, policies related to Education of the Handicapped funds should not prevent such funds from paying for assistive technology.

Vocational Rehabilitation Services

The Rehabilitation Reauthorization Act of 1986 (PL 99-506) requires that state vocational rehabilitation programs place greater emphasis on rehabilitation technology and engineering services to assist an increasing number of individuals with handicaps. While recognizing the need for a greater emphasis on using assistive technology to meet the needs of individuals with disabilities, Congress did not provide additional appropriations to carry its mandate to increase the use of assistive technology. As a result, states will need to make difficult decisions about reallocations of existing funds in order to provide and pay for necessary assistive technology that will enhance a client's ability to benefit from vocational rehabilitation.

Each client in the vocational rehabilitation program must have an Individualized Written Rehabilitation Plan (IWRP). The

IWRP must include all of the programs and services needed by an individual to benefit from the vocational rehabilitation program. Historically, the vocational rehabilitation program has provided and paid for some assistive technology. However, as the technology has developed rapidly over the past few years, the available funding has been limited while Congress' recognition of the need has increased.

Unfortunately, vocational rehabilitation programs have received little federal guidance on establishing criteria for determining eligible clients for advanced assistive technology or developing guidelines for making decisions concerning reallocation of resources to help an increasing number of individuals with disabilities. Additionally, few states employ speech-language pathologists and audiologists as consultants who can best assist in coordinating appropriate rehabilitation service with assistive technology.

Supplemental Security Income

The Supplemental Security Income (SSI) program administered by the Social Security Administration currently provides a disincentive for SSI recipients to accumulate enough savings to purchase necessary assistive technology. The current social security law does not allow a recipient to acquire assets above a certain level. As a result, recipients are not able to accumulate the funds needed to purchase assistive technology.

Internal Revenue Code

Recent changes in the Internal Revenue Code have limited the usefulness of the medical deduction. Because a person must expend a great amount (7%) of adjusted net income to be eligible for any medical deduction, this indirect subsidy has been rendered essentially useless for the deductions related to the purchase of assistive technology.

There are other tax changes being discussed in the House of Representatives which could have the impact of excluding universities and non-profit charitable organizations from providing assistive technology to handicapped persons. The Subcommittee on Oversight of the Committee on Ways and Means is considering applying the federal corporate income tax to every non-profit institution which provides medical equipment or devices such as hearing aids, even if that service is substantially related to the tax-exempt purpose of the organization, and even if the sales are limited to low-income persons. While no legislation has yet been proposed, this committee needs to be aware that many non-profit organizations who have been leaders in developing and delivering these new technologies may have the indirect subsidy of federal tax exemption repealed, thus increasing the costs of these devices and adding new paperwork to the current "maze."

Other Funding Sources

Programs such as those provided under the Developmental Disabilities Act, the Older Americans Act, and Maternal and Child Health may or may not provide funding for assistive technology.

Conclusion

This discussion is intended to show that there are a variety of existing and potential funding sources for assistive technology. Yet, no single and coordinated comprehensive funding source for assistive technology can be identified. A review of existing reimbursement and funding programs finds that most of them are administered at the state level by a variety of agencies. Clearly, the evidence shows that there is a lack of coordination among the various agencies. Is it any wonder that individuals with disabilities and the professionals attempting to provide efficient and effective services are bewildered about what can and cannot be reimbursed in the area of assistive technology?

RECOMMENDATIONS

If one must navigate successfully through the maze of existing funding and reimbursement systems related to assistive technology, obvious changes are needed. The following are some specific recommendations and an option we believe will alleviate current problems related to funding and reimbursement of assistive technology. Many of the recommendations relate to the current uncoordinated funding programs. Regardless of the changes made in the individual programs, there is a need to develop a national coordinated assistive technology financing program.

1. Amend the Medicare and Medicaid program to expand the definition of durable medical equipment to include assistive technology that is not presently covered.

2. Amend the Education of the Handicapped Act, Developmental Disabilities Act, and Rehabilitation Act to clarify that assistive technology needs should be included in any individualized service plan and that the costs of assistive technology could be paid with funds from these programs.

3. Amend the Supplemental Security Income program policies to give recipients an opportunity to accumulate assets that exceed specified eligibility asset levels. Additional assets would be earmarked to obtain assistive technology.

4. Amend the Internal Revenue Code to provide tax credits, tax deductions, accelerated write-offs or other incentives that could be used by individuals who purchase assistive technology.

Option

Establish a National Assistive Technology Funding Commission to study issues related to funding for assistive technology. The Commission would be charged with recommending a combined public/private program to ensure that individuals needing assistive technology would have access to necessary aids and devices and would have adequate funding and financing programs to purchase required assistive technology.

The Commission could:

1. Create a program that would provide federal subsidies in the form of low-interest loans, guaranteed loans, revolving loan funds and lend-lease programs.

2. Establish a separate assistive technology funding program that would provide a single stream of funding for purchase of necessary assistive technology.

3. Provide funds to states to identify state programs that could pay for assistive technology and to develop coordinated procedures so individuals needing assistive technology would be able to obtain services and equipment.

These recommendations and the option are designed to allow for development of both public and private sector payment support opportunities. It is recommended that Congress consider both the development of funding programs that would enable government or private groups to pay for most or all of the cost of obtaining assistive technology for the individual, and the development of financing programs that would provide incentives for individuals to use their own resources to obtain assistive technology.

SUMMARY

A review of existing public and private reimbursement sources for assistive technology finds a complex and disjointed maze confronting both the consumer and professional. Laws and regulations are unclear as to what assistive technology can and cannot be paid for under various programs; there are few incentives that encourage the use of personal funds to obtain assistive technology; and everyone wants to be the payor-of-last-resort. There is a great need to coordinate existing public and private funding programs or to establish a single program specifically for funding and financing assistive technology. There definitely needs to be a payor-of-first-resort.

The developments and advances in assistive technology over the past few years have and will increase the opportunities for individuals with disabilities to use such technology to increase mobility, communication, employment opportunities and the quality of life. The demand for assistive technology by individuals with disabilities will only increase as advances in technology are made. The need for coordinated, accessible, comprehensive funding and financing programs will also increase.

In summary, the present reimbursement system is not meeting the assistive technology needs of individuals with disabilities. We encourage Congress to take action that will lead to a reimbursement program that will assure access to assistive technology by those Americans who strive to become productive citizens and improve their quality of life.

Mr. Chairman, I thank you and the members of the Committee for this opportunity to testify before you. The American Speech-Language-Hearing Association and its members look forward to working with you as you pursue solutions to providing assistive technology for individuals with disabilities.

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Senator **Harkin**. Thank you very much for your testimony, and for being here.

Next is Mary Pat Radabaugh, who is founder and Manager of the IBM National Support Center for Persons with Disabilities.

We are pleased to have you here, welcome, and please proceed.

Ms. **Radabaugh**. Thank you, Mr. Chairman, and thank you for the opportunity to share our perspective with you on technology for persons with disabilities.

For most of us, technology makes things easier. For people with disabilities, technology can make things possible. Our center was formed in 1985 to be IBM's focal point for information on how our technology can help. It was formed as a social responsibility program.

We believe there are four key areas requiring attention, both in the public and private sector. What I would like to do is share with you our experience in those four areas and where we see recommendations to help. The areas are: awareness, affordability, training and jobs.

I believe one of the best-kept secrets today is the capability of technology and what it can do to help people who need help. Raising the level of awareness was the first key mission we launched when we established our center in 1985.

In 1987 alone, we logged over 19,000 inquiries through the mail and through our toll-free 800 number. They confirmed the enormous pent-up demand for information that we saw from the beginning when we established the center. In the last 12 months, we have exhibited at over 60 shows, symposiums and conferences. We do customer executive briefings for educators, social service agencies, Government leaders, and our customers, several times a week, typically.

We advertise, on a national level, with national television spots, what the technology can do and what services we provide, including where people can get information from us. But probably the most significant proactive program we have launched, about a year ago, is our Executive Awareness Program.

Basically, it is a 90-minute briefing that we travel around the country and take to communities, targeted at educators, rehab professionals, individuals, leaders in the public sector, our customers and the press, to spread the word about what technology can do and where to get the information. Again, they have confirmed the pent-up demand for the information. Typically, we do four to five sessions a day for about a week in each city.

What we believe is that people don't know that there is information there, and they don't know where to start to get it. What we recommend is that there be a broader based public information program, including public service broadcasts, advertising what is possible and where to go for help. Another key is the establishment of resource or demo centers where people can see, feel, and work with the technology, easily accessible on a local basis.

After you raise the level of awareness, the next problem becomes affordability. Other people have testified to this. I would like to share with you our program we announced in late 1987, the IBM Offering for Persons with Disabilities. It's now available in 10 locations across the country and, basically, it provides a way for people with disabilities to purchase computers more easily; basically at our deepest discount of approximately 40 to 50 percent.

But it is more than a discount program; it's a partnership with social service agencies, the first of which is National Easter Seals, where they provide comprehensive one-on-one assistance to the individuals, from assessment all the way through installation, including in the person's home, if that is where they need it. But for people on fixed disability incomes, those discount programs are not enough. More is needed.

We have several suggestions we would like to share with you regarding affordability. You asked earlier about Medicaid, and we had several people talk about Medicaid and insurance. We believe also that the provisions should be expanded to include the technology as "medical necessities" or "prosthetic devices." Equipment financing or low-cost loans could help. Tax credits for the purchasers of the technology could help.

Also, the assistive device business itself is a cottage industry, primarily. We believe the Government could encourage new business to enter the field, or existing companies to develop more technology and innovative ways of using the technology and thereby provide better availability and more competitively priced products.

Once you do the awareness and affordability, training becomes the next key. Through joint funding from IBM in a GSA joint project with industries project, IBM has helped establish over 36 training centers across the country for disabled people to learn how to become programmers. Their common goal is to train the disabled people and also place the graduates in competitive jobs.

We also have added data entry, word processing, computer assisted design and customer service training to that programmer training in many of the centers. So far, we have placed over 2,000 graduates just in the programming positions alone, and the 1987 graduates started at an average salary of $20,000 per year. But not enough vocational training is in place in this country today, based on the tremendous size of the unemployed disabled adult men and women.

We have some possible solutions. The technology or demo resource centers we recommended earlier could also include training like the training we talked about in these particular centers across the country, with the minimum goal of one per state, whether you combine them with the demo centers or provide separate training facilities themselves. Also, certification requirements for educators and rehab professionals should include a knowledge of assistive technology. "Teach the teachers" is the way I like to put it.

One key goal, obviously, is jobs. At IBM we focus on people's ability—not their disability—and IBM managers are required to design jobs focusing on people's abilities and minimizing the restrictions a disability may pose. Last year we put in place a training program, company-wide, for all managers, called "Enabling the Disabled" that focused on sensitivity issues and how to manage, hire, recruit, and promote disabled employees. The ultimate objective of all assistive technology is improve the quality of living for all persons with disabilities.

We have several thoughts on improving employment opportunities. We talked earlier about the Architectural Barrier Tax Provision provided for people with disabilities. Basically, we believe that ought to be expanded to include computer technology or assistive devices.

Second, incentives and/or recognition for replicable management training programs would lead to more jobs. That information, those successful programs could then be disseminated, for example, to small businesses to improve, again, the hiring, training and employability.

I believe it's a test of our society, a test of our civilization in how well we use technology to enrich everyone's lives. We can help people if we believe in the dignity and importance of life, and of the need to find ways to enhance the quality of life for all of our citizens.

Mr. Chairman, computer technology does not change the disability, but it can change the environment. It can minimize, and often eliminate, the handicap of the environment.

Thank you very much.

[The prepared statement of Ms. Radabaugh with an attachment follows:]

STATEMENT

BY

MS. MARY PAT RADABAUGH, MANAGER

IBM NATIONAL SUPPORT CENTER FOR PERSONS WITH DISABILITIES

BEFORE THE

SENATE SUBCOMMITTEE ON THE HANDICAPPED

MAY 20, 1988

MR. CHAIRMAN, MEMBERS OF THE COMMITTEE:

ON BEHALF OF THE IBM NATIONAL SUPPORT CENTER FOR PERSONS WITH DISABILITIES, WE WANT TO THANK YOU FOR THE OPPORTUNITY TO SHARE OUR PERSPECTIVE ON TECHNOLOGY FOR PEOPLE WITH DISABILITIES.

OVER THE YEARS, IBM HAS BEEN DEVELOPING AND PROMOTING THE USE OF NEWER AND BETTER TECHNOLOGY. THE CRITICAL CHALLENGE HAS BEEN TO FIND WAYS TO APPLY THAT TECHNOLOGY DIRECTLY TO ENRICH PEOPLE'S LIVES. TODAY, THANKS MAINLY TO THE POWER AND AFFORDABILITY OF COMPUTERS, WE ARE ABLE TO HARNESS TECHNOLOGY TO MAKE A REAL DIFFERENCE IN THE LIVES OF PERSONS WITH DISABILITIES.

LINKING COMPUTERS TO A WIDE VARIETY OF DEVICES AND EQUIPMENT HAS NOW OPENED DOORS PREVIOUSLY THOUGHT TO BE CLOSED. THOSE WHO CANNOT SPEAK CAN NOW COMMUNICATE WITH VOICE SYNTHESIZERS. THOSE WHO CANNOT HEAR NOW "CONVERSE" OVER PHONE LINES. THOSE WHO CANNOT SEE CAN NOW "READ BY LISTENING" TO A COMPUTER. THOSE WHO CANNOT MOVE CAN NOW COMMUNICATE WITH A TWITCH OF A MUSCLE OR THE BLINK OF AN EYELID. AND THOSE WHO HAVE DIFFICULTY LEARNING CAN NOW BECOME MORE PRODUCTIVE CITIZENS THROUGH THE ALMOST LIMITLESS CAPABILITY OF COMPUTER-DRIVEN LEARNING.

IN 1985 THE IBM NATIONAL SUPPORT CENTER FOR PERSONS WITH DISABILITIES WAS ESTABLISHED AS A CORPORATE RESPONSIBILITY PROGRAM TO BE THE COMPANY'S FOCAL POINT FOR INFORMATION ON HOW OUR

TECHNOLOGY CAN HELP. AND, WHILE MUCH PROGRESS HAS BEEN MADE IN TECHNOLOGICAL SUPPORT OF PERSONS WITH DISABILITIES, WE BELIEVE THERE ARE FOUR KEY AREAS WHICH REQUIRE INCREASED FOCUS AND ATTENTION IN BOTH THE PRIVATE AND PUBLIC SECTORS. THESE AREAS ARE:

- AWARENESS
- AFFORDABILITY
- TRAINING
- JOBS

I WILL SHARE WITH YOU OUR INITIATIVES AND ACTIVITIES IN THESE AREAS, AND OUR EXPERIENCE REGARDING PROBLEMS IN PROVIDING THE TECHNOLOGY TO PERSONS WITH DISABILITIES.

AWARENESS

WE BELIEVE ONE OF THE "BEST-KEPT SECRETS" IN OUR SOCIETY IS THE CURRENT CAPABILITY OF TECHNOLOGY TO ASSIST PEOPLE WITH DISABILITIES. OUR CENTER CONSIDERS RAISING THE LEVEL OF AWARENESS OF THIS TECHNOLOGY AS A KEY PART OF OUR MISSION. IN 1987 ALONE, WE LOGGED OVER 19,000 INQUIRIES THROUGH THE MAIL AND TO OUR TOLL FREE 800 NUMBER. IN THE ATTACHMENT YOU WILL FIND AN EXAMPLE OF THE INFORMATION WE MAIL OUT IN RESPONSE TO AN INQUIRY.

WE HAVE DISCOVERED AN ENORMOUS PENT-UP DEMAND FOR INFORMATION ON ASSISTIVE TECHNOLOGY. FOR INSTANCE, IN THE LAST 12 MONTHS, WE'VE EXHIBITED AT MORE THAN 60 SHOWS, CONFERENCES AND SYMPOSIUMS. WE CONDUCT EXECUTIVE BRIEFINGS TO EDUCATORS, AGENCY AND GOVERNMENT LEADERS, AND OUR CUSTOMERS.

WE ADVERTISE THE CAPABILITIES OF TECHNOLOGY AND THE SERVICES OF OUR CENTER ON A NATIONAL LEVEL THROUGH A TELEVISION SPOT WHICH HAS BEEN AIRING OVER THE LAST EIGHT MONTHS. PROBABLY OUR MOST SIGNIFICANT PROACTIVE PROGRAM IS "EXECUTIVE AWARENESS." THIS 90-MINUTE BRIEFING IS A TRAVELING DEMONSTRATION AND PRESENTATION TARGETED TO EDUCATORS, REHABILITATION PROFESSIONALS, INDIVIDUALS, LEADERS IN THE PUBLIC SECTOR, CUSTOMER EXECUTIVES AND THE PRESS. THESE SESSIONS HAVE CONFIRMED AGAIN THE INCREDIBLE INTEREST IN INFORMATION ON ASSISTIVE TECHNOLOGY. THOUGH MUCH INFORMATION IS AVAILABLE, PEOPLE DON'T KNOW IT'S THERE, NOR HOW TO GET AT THE INFORMATION.

WHAT IS NEEDED, IN OUR VIEW, IS A MUCH BROADER BASED PUBLIC INFORMATION PROGRAM -- MUCH BROADER THAN WHAT WE HAVE BEEN ABLE TO DO WITH OUR PROGRAMS -- TO LET PEOPLE KNOW WHAT TECHNOLOGY IS AVAILABLE. THE PROGRAM COULD INCLUDE PUBLIC SERVICE BROADCASTS ADVERTISING WHAT'S POSSIBLE AND WHERE TO GO FOR HELP.

ANOTHER KEY TO INCREASING AWARENESS IS TO TIE THE INFORMATION PROGRAMS INTO RESOURCE/DEMONSTRATION CENTERS WHERE PEOPLE CAN GO TO SEE, FEEL, AND WORK DIRECTLY WITH THE TECHNOLOGY. THESE CENTERS SHOULD BE EASILY ACCESSIBLE ON A LOCAL BASIS.

AWARENESS IS A FIRST STEP. BUT ONCE THE CAPABILITIES OF ASSISTIVE TECHNOLOGY ARE KNOWN, PURCHASING THE EQUIPMENT CAN BE ANOTHER BARRIER. THE PROBLEM THEN BECOMES . . .

AFFORDABILITY

IN 1987 IBM ANNOUNCED THE IBM OFFERING FOR PERSONS WITH DISABILITIES TO MAKE IT EASIER FOR THEM AS INDIVIDUALS TO PURCHASE COMPUTERS FOR REHABILITATIVE AND THERAPEUTIC PURPOSES. THROUGH THIS OFFERING -- NOW AVAILABLE IN 10 GEOGRAPHIC LOCATIONS -- ELIGIBLE DISABLED RESIDENTS CAN PURCHASE SELECTED PERSONAL COMPUTING PRODUCTS AND ADAPTIVE HARDWARE AND SOFTWARE AT IBM'S DEEPEST COMMERCIAL DISCOUNT OF APPROXIMATELY 40 - 50 %.

THE OFFERING IS MORE THAN JUST A DISCOUNT PROGRAM. IT IS A PARTNERSHIP WITH COMMUNITY SERVICE ORGANIZATIONS, THE FIRST OF WHICH IS THE NATIONAL EASTER SEAL SOCIETY. AS PART OF THIS PROGRAM, EASTER SEAL PROVIDES COMPREHENSIVE ONE-ON-ONE ASSISTANCE BEFORE AND AFTER THE SALE AT NO CHARGE TO THE INDIVIDUAL. THIS PROGRAM WITH THE EASTER SEAL SOCIETY IS DESCRIBED IN ONE OF THE PAMPHLETS ATTACHED.

BUT FOR MANY ON FIXED DISABILITY INCOME, THIS DISCOUNT IS NOT ENOUGH. MORE IS NEEDED TO MAKE ASSISTIVE DEVICES BROADLY AFFORDABLE. WE HAVE SEVERAL SUGGESTIONS ON HOW THIS MIGHT BE ADDRESSED: FOR INSTANCE, MEDICAID AND INSURANCE PROVISIONS SHOULD BE EXPANDED TO INCLUDE COMPUTER TECHNOLOGY AND

ASSISTIVE DEVICES AS MEDICAL NECESSITIES OR DEFINED AS PROSTHETIC DEVICES. EQUIPMENT FINANCING AND/OR LOW-COST LOANS COULD HELP. TAX CREDITS FOR PURCHASERS OF ASSISTIVE TECHNOLOGY COULD ALSO MOTIVATE MORE EMPLOYERS TO PROVIDE EMPLOYMENT OPPORTUNITIES WITH ASSISTIVE TECHNOLOGY AS A WORKPLACE ACCOMMODATION.

THE ASSISTIVE DEVICE BUSINESS IS PRIMARILY A COTTAGE INDUSTRY. THE GOVERNMENT COULD ENCOURAGE NEW BUSINESS TO ENTER THIS FIELD OR EXISTING COMPANIES TO DEVELOP NEW TECHNOLOGY THROUGH TAX INCENTIVES, THEREBY PROVIDING NEW AND INNOVATIVE SOLUTIONS AND IMPROVING OVERALL AVAILABILITY AND COMPETITIVE PRICING.

AWARENESS AND AFFORDABILITY ARE NOT THE TOTAL ANSWER. THE PERSON MUST STILL GET HELP IN LEARNING TO USE THE EQUIPMENT AND ASSISTANCE IN FINDING A PLACE TO WORK.

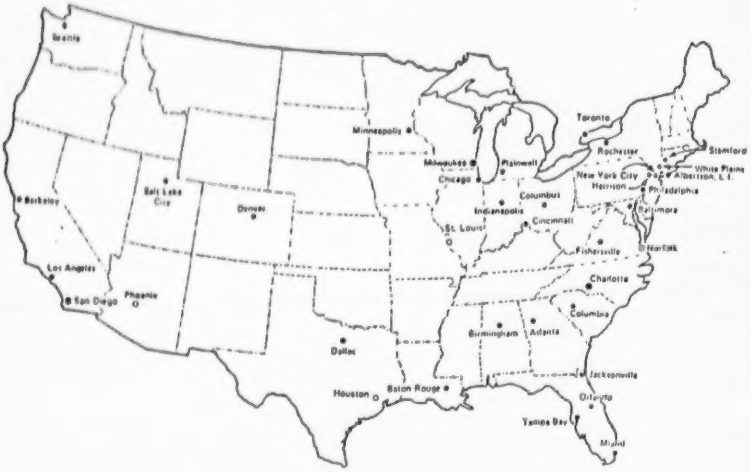
TRAINING

. . .

IS CERTAINLY THE NEXT STEP. IBM HAS BEEN ASSISTING STATE REHABILITATION AGENCIES TO DEVELOP AND MAINTAIN TRAINING AND PLACEMENT PROGRAMS FOR SEVERELY PHYSICALLY DISABLED PERSONS SINCE 1972. UTILIZING JOINT FUNDING FROM IBM AND AN RSA PROJECT WITH INDUSTRY CONTRACT, WE HAVE HELPED TO ESTABLISH TRAINING PROJECTS ACROSS THE NATION. THE 36 CURRENTLY OPERATING TRAINING PROJECTS HAVE A COMMON GOAL: TO TRAIN QUALIFIED, SEVERELY PHYSICALLY DISABLED PERSONS AS COMPUTER PROGRAMMERS AND TO

PLACE THOSE WHO SUCCESSFULLY COMPLETE THE TRAINING IN COMPETITIVE PROGRAMMING POSITIONS.

IBM PROJECT TO TRAIN THE DISABLED
JANUARY 1988


Seattle
Toronto
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Berkeley
Columbus
Denver
Indianapolis
Baltimore
Cincinnati
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Fishersville
Norfolk
Los Angeles
Charlotte
San Diego
Phoenix
Columbia
Birmingham
Atlanta
Dallas
Jacksonville
Houston
Baton Rouge
Orlando
Tampa Bay
Miami

IN ADDITION, SEVERAL OF THE LOCATIONS HAVE TAKEN THE IBM MODEL AND IMPLEMENTED ADDITIONAL TRAINING PROGRAMS FOR PERSONS WITH DISABILITIES IN DATA ENTRY, WORD PROCESSING, COMPUTER ASSISTED DESIGN, CUSTOMER SERVICE, ETC.

THE COMPUTER PROGRAMMER TRAINING PROGRAMS HAVE PLACED OVER 2000 GRADUATES IN PROGRAMMING POSITIONS, ALONE. THE AVERAGE SALARY FOR GRADUATES PLACED IN 1987 WAS APPROXIMATELY $20,000 PER YEAR.

BASED ON OUR EXPERIENCE, THERE ARE NOT ENOUGH VOCATIONAL TRAINING PROGRAMS IN PLACE TODAY IN THIS COUNTRY. THE SIZE OF THE POPULATION OF UNEMPLOYED DISABLED MEN AND WOMEN IS WITNESS TO THIS PROBLEM.

ANOTHER KEY IN THE TRAINING PROCESS IS THE AVAILABILITY OF THE LOCAL TECHNOLOGY RESOURCE AND DEMONSTRATION CENTERS -- WHICH WE RECOMMENDED EARLIER AS PART OF ENHANCING AWARENESS. THESE LOCATIONS COULD SERVE AS TRAINING CENTERS AS WELL. BUT WHETHER AS SEPARATE TRAINING CENTERS OR COMBINED WITH DEMONSTRATION CENTERS, THERE SHOULD BE A MINIMUM GOAL OF A TRAINING FACILITY IN EACH STATE.

IN ADDITION, WE BELIEVE CERTIFICATION REQUIREMENTS FOR EDUCATORS AND REHABILITATION PROFESSIONALS COULD INCLUDE KNOWLEDGE OF ASSISTIVE TECHNOLOGY.

ONE OF THE KEY GOALS OF ALL OF THESE EFFORTS CONTINUES TO BE THE AVAILABILITY OF . . .

JOBS

IBM HAS A 73-YEAR TRADITION OF SUPPORT FOR DISABLED PERSONS. SINCE HIRING ITS FIRST DISABLED EMPLOYEE IN 1914, THE COMPANY HAS BEEN COMMITTED TO HIRING AND ACCOMMODATING DISABLED EMPLOYEES.

AT IBM, WE HIRE PEOPLE BASED ON THEIR ABILITIES, NOT THEIR DISABILITIES. THIS PRACTICE IS AN EXTENSION OF THE COMPANY'S BASIC BELIEF IN RESPECT FOR THE INDIVIDUAL.

TODAY, IBM HAS ABOUT 7,000 DISABLED EMPLOYEES IN THE UNITED STATES IN A VARIETY OF POSITIONS THROUGHOUT THE COMPANY.

IBM MANAGERS HAVE A RESPONSIBILITY TO DEFINE JOB REQUIREMENTS TO TAKE ADVANTAGE OF A PERSON'S ABILITIES AND TO MINIMIZE RESTRICTIONS A DISABILITY MAY POSE. TO HELP MANAGERS MEET THAT GOAL, THE COMPANY HAS DEVELOPED A TRAINING MODULE TITLED "ENABLING THE DISABLED" WHICH FOCUSES ON VARIOUS ASPECTS OF MANAGING DISABLED EMPLOYEES.

IBM ATTEMPTS TO ACCOMMODATE DISABLED EMPLOYEES AND MINIMIZE ENVIRONMENTAL RESTRICTIONS IN THE WORK PLACE. WHENEVER POSSIBLE, WE MAKE NECESSARY ACCOMMODATIONS TO PROVIDE ACCESS TO OUR FACILITIES AND OFFICES AND MAKE AVAILABLE ADAPTIVE DEVICES TO MINIMIZE THE EFFECT OF AN EMPLOYEE'S DISABILITY. THE ULTIMATE OBJECTIVE OF ALL ASSISTIVE TECHNOLOGY IS TO IMPROVE THE QUALITY OF LIFE FOR PERSONS WITH DISABILITIES. IMPROVING EMPLOYMENT OPPORTUNITIES, OBVIOUSLY, IS KEY.

WE HAVE SEVERAL THOUGHTS TO SHARE WITH YOU ON HOW TO EXPAND EMPLOYMENT OPPORTUNITIES. FIRST, THE $35,000 ARCHITECTURAL BARRIER TAX PROVISION FOR COMPANIES THAT HIRE PERSONS WITH DISABILITIES COULD BE EXPANDED TO INCLUDE TAX PROVISIONS FOR THE COST OF TECHNOLOGY ACCOMMODATIONS.

SECOND, INCENTIVES AND/OR RECOGNITION FOR REPLICABLE MANAGEMENT TRAINING PROGRAMS REGARDING ASSISTIVE TECHNOLOGY, RECRUITING, HIRING, TRAINING AND PROMOTING PERSONS WITH DISABILITIES COULD PROVIDE ULTIMATELY MORE JOBS FOR DISABLED PEOPLE. THESE SUCCESSFUL PROGRAMS COULD THEN BE DISSEMINATED FOR INCORPORATION IN OTHER BUSINESSES, THUS ENCOURAGING AWARENESS OF THE BUSINESS MANAGEMENT WHO ACTUALLY DO THE RECRUITING AND HIRING.

BUT IT ISN'T JUST IN THE WORKPLACE THAT TECHNOLOGY CAN HAVE AN EFFECT. TECHNOLOGY CAN ALSO DRAMATICALLY IMPROVE THE QUALITY OF LIFE FOR DISABLED PEOPLE IN THE CLASSROOM AND IN THE HOME. ONE VERY VIVID EXAMPLE OF THIS IS OF A WOMAN WHO HAS LOU GEHRIG'S DISEASE, AND WHO CAN ONLY COMMUNICATE WITH HER EYEBROWS. AND THAT IS WHERE TODAY'S TECHNOLOGY COMES IN. THROUGH THE DISPLAY SCREEN OF A COMPUTER AND WITH HER EYEBROWS THIS WOMAN IS ABLE TO WRITE DOWN SOME OF HER FAVORITE RECIPES -- AND THEREBY PASS ON HER COOKING SKILLS TO HER KIDS.

AND THEN THERE'S THE STORY ABOUT THE 15 YEAR OLD DEAF BOY WHO ATTENDED A "MAINSTREAM" SCHOOL. NONE OF HIS FRIENDS HAD HEARING PROBLEMS, AND SO HE WAS EXCLUDED FROM A TEENAGER'S FAVORITE PASTIME -- TALKING ON THE PHONE. HIS FAMILY CONTACTED OUR CENTER AND FOUND OUT ABOUT "AUGMENTED PHONE SERVICES", AN IBM PRODUCT THAT ALLOWED THE TEENAGER TO HOOK HIS PERSONAL COMPUTER UP TO THE PHONE AND "TALK" WITH HIS FRIENDS. WELL, SHORTLY AFTER INSTALLING THE "AUGMENTED PHONE SERVICES", THIS 15 YEAR OLD BOY GOT HIS FIRST DATE....AND THE GIRL "CALLED" HIM!

JUST THINK HOW MUCH THIS TEENAGER'S ENTIRE LIFE EXPANDED WHEN HE FINALLY REALIZED THAT HIS HEARING "DISABILITY" WASN'T GOING TO BE SUCH A "HANDICAP" AFTER ALL.

THE HOPE...THE PROMISE...THE OPPORTUNITY THAT TECHNOLOGY OFFERS US IS AS WIDE-RANGING AS HUMAN ACTIVITY ITSELF...FROM PEOPLE ANXIOUS TO GET A JOB...TO A SERIOUSLY-ILL MOTHER COMMUNICATING WITH HER CHILDREN...TO A SHY TEENAGER COMMUNICATING WITH HIS FRIENDS.

I BELIEVE THAT IT'S A TEST OF OUR SOCIETY...A TEST OF OUR CIVILIZATION...IN HOW WE USE TECHNOLOGY TO ENRICH OUR LIVES. WE CAN HELP PEOPLE IF WE BELIEVE IN THE DIGNITY AND IMPORTANCE OF LIFE, AND OF THE NEED TO FIND WAYS TO ENHANCE THE QUALITY OF LIVING FOR ALL OF OUR CITIZENS.

COMPUTER TECHNOLOGY DOES NOT CHANGE THE DISABILITY, OF COURSE, BUT IT DOES CHANGE THE ENVIRONMENT. IT CAN MINIMIZE, AND PERHAPS ELIMINATE, THE "HANDICAP" OF THAT ENVIRONMENT. FOR MOST OF US, TECHNOLOGY MAKES THINGS EASIER; FOR PERSONS WITH DISABILITIES TECHNOLOGY CAN MAKE THINGS POSSIBLE.

IBM

NATIONAL SUPPORT CENTER FOR PERSONS WITH DISABILITIES

The IBM National Support Center for Persons with Disabilities was created to help health care leaders, agency directors, policy makers, employers, educators, public officials and individuals learn how technology can improve the quality of life for the disabled person in the school, home and work place.

The Center responds to requests for information on how computers can help people with vision problems, hearing problems, speech impairments, learning disabilities, mental retardation and mobility problems. While the Center is unable to diagnose or prescribe an assistive device or software, information is provided on what is available and where one can go for more details.

We invite your inquiries on these assistive devices, software and services for disabled persons.

IBM National Support Center for Persons with Disabilities
P. O. Box 2150
Atlanta, GA 30055

1-800-IBM-2133 (Continental USA Voice/TDD)
404/988-2733 (Georgia Voice Only)
404/988-2729 (Georgia TDD Only)

People Helping People Through Technology

Corporate Information
IBM Corporation
Old Orchard Road
Armonk, New York 10504

Information About:

CONTACT: Rita A. Black
(914) 765-6408

IBM SUPPORT FOR PERSONS WITH DISABILITIES

IBM has a 74-year tradition of support for disabled persons. Since hiring its first disabled employee in 1914, the company has been committed to hiring and accommodating disabled employees. That commitment extends into the community as well. Working with community-based groups, the company has helped develop training courses, contributed funding and equipment, and loaned employees to programs that benefit persons with disabilities.

IBM also is developing and promoting technology to help persons with disabilities lead full and productive lives. The company's National Support Center for Persons with Disabilities serves as an information clearinghouse and showcase for products and agencies available to the disabled. In addition, IBM has established the Special Needs Systems, Special Needs Initiatives and Programs, and other departments to develop products, promote research, and work with community and educational organizations to assist persons with disabilities.

Commitment to Hiring Disabled Persons

At IBM, we hire people based on their abilities, not their disabilities. This practice is an extension of the company's basic belief in respect for the individual. Under that practice, hiring is administered without regard to race, color, religion, sex, national origin, age, or disability.

Today, IBM has about 7,000 disabled employees in the United States in a variety of positions throughout the company.

IBM managers have a responsibility to define job requirements to take advantage of a person's abilities and to minimize restrictions a disability may pose. To help managers meet that goal, the company has developed a training module titled "Enabling the Disabled" which focuses on various aspects of managing disabled employees.

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Accommodating Persons With Disabilities

IBM attempts to accommodate disabled employees and minimize environmental restrictions in the work place. Whenever possible, we make necessary accommodations to provide access to our facilities and offices and make available adaptive devices to minimize the effect of an employee's disability. These accommodations include:

- -- Constructing ramps, entrances, parking facilities and other accommodations to provide access for people with impaired mobility.
- -- Captioning videotapes, and providing sign language interpreters and note takers for classes and meetings for people who are hearing impaired.
- -- Recording employee bulletin board notices on audio cassettes for the vision impaired.
- -- Providing adaptive devices or modifications to enable disabled persons to use computers, telephones, typewriters and other work-related equipment. Some examples are talking terminals and display screen magnifiers for the sight impaired, special switches and voice-activated keyboards for the mobility impaired, and telephone amplifiers and telecommunications devices for the hearing impaired.

Supporting Disabled Persons in the Community

In 1987, IBM provided more than $800,000 to support programs serving persons with disabilities -- establishing programs, contributing funds and equipment, and loaning employees to a variety of organizations. Some examples are:

- -- Supported 36 Programmer Training Centers for physically disabled people nationwide. In partnership with community-based organizations, the centers have provided training and job assistance in computer programming for more than 2,400 graduates since 1972.
- -- Provided equipment and funding to Gallaudet University, Washington, D.C., to establish a unique interactive English training program for hearing impaired students and an information network accessible by other educators.
- -- Contributed more than $400,000 through the IBM Fund for Community Service, which provides funds to programs in which employees are actively involved.
- -- Purchased more than $20 million in goods and services from approximately 60 companies predominantly employing disabled individuals.
- -- Loaned employees to Gallaudet University, the United Cerebral Palsy Association, and other organizations dealing with disabled persons as part of IBM's Community Service Assignment and Faculty Loan programs.

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Establishing an Information Clearinghouse

In 1985, IBM established the National Support Center for Persons with Disabilities in Atlanta, Georgia. The center demonstrates and provides information on IBM and non-IBM equipment, along with services available for persons with a range of disabilities, including those who are sight, hearing and mobility impaired.

The center operates a toll-free hotline that provides information about the products and agencies. The hotline (800-IBM-2133 for voice/TDD; in Georgia, 404-988-2733 for voice and 404-988-2729 for TDD) receives more than 1,500 calls per month. The center also provides demonstration tours to disabled persons, employers, state and federal government officials, international organizations, and others.

Developing New Products for Disabled Persons

IBM reaffirmed its commitment to developing equipment for persons with disabilities in 1986 by creating the Special Needs Systems department. Located in Boca Raton, Florida, the department oversees the development and manufacturing of IBM products for disabled persons. In January 1988, IBM introduced the IBM Personal System/2 Screen Reader, a product that lets blind or visually-impaired users hear text just as a sighted user would see it displayed on a screen. It is the first member of the IBM Independence Series of products designed for computer users with special needs.

IBM also is involved in research to develop future product applications for the disabled. The Special Needs Initiatives and Programs office, based in New York, reviews product design for accessibility to the disabled and coordinates research projects for disabled persons.

Promoting Research and Other Support

IBM also is working with educational institutions and community organizations to promote further research on equipment and to develop services for persons with disabilities. The Special Education Programs Department works in partnership with educators and researchers to foster technology to assist youths who have special learning needs. IBM's Academic Information Systems (ACIS) extends the support to students and educators at universities. For example, ACIS establishes joint studies and supports research on ways technology can help educators and therapists identify and aid persons with disabilities. ACIS also promotes other projects to directly assist disabled persons both on and off campus.

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Senator HARKIN. Thank you very much for a very fine statement.

Our last witness is Dr. Larry Scadden of Electronic Industries Foundation. Dr. Scadden will present information on research and development of assistive technology. Please proceed.

Dr. SCADDEN. Thank you, Mr. Chairman. I appreciate the opportunity to provide another perspective from industry in the area of assistive technology.

Industry will provide quality assistive technology and devices for people with disabilities when a financially-based market demand exists. Policies and practices of the Federal Government can either promote or hinder industry's participation in this endeavor. The role of the Federal Government should be to stimulate the marketplace for assistive technology and the human services essential to support product selection and user training.

The Federal Government should stimulate the market demand for assistive techology by improving the financial capacity of the people with disabilities to acquire the needed technology and the services to support it. Increased personal income, acquired through productive, gainful employment is the most logical and dignified means for them to acquire this capacity.

Assistive technology can frequently improve competitive job performance, both at the entry level as well as for upward career mobility. Thus, policies and programs that facilitate employment through the use of assistive technology for employment-related activities is paramount.

The Federal Tax Code should continue to provide disabled individuals tax deductions for the purchase or lease of technology used in employment, but these credits or these deductions should be extended to other parts of personal life, and it should be extended to cover families' expenses when they are providing the technology for their dependents. Tax considerations should also be given to employers who purchase or lease assistive technology for their employees. We support the passage of your bill, S. 1806.

The Federal Government should initiate demonstration programs to study the feasibility and efficacy of operating Federal Government loan guarantee programs for assistive technology purchases made by people with disabilities. The Federal Government should stimulate state and local efforts to establish and operate assistive technology support programs.

These jurisdictions are the ones that are in charge of managing and spending the $60 billion that was mentioned earlier, money that is used in welfare, health care and employment programs. A well-managed and coordinated effort to use a portion of these funds for the purchase and maintenance of assistive technologies for people with disabilities would be very cost-effective.

We believe that demonstration programs should be established in states—in a few states, maybe 5 or 10 at the outset—to establish workable models, to find which model will work best in urban, which best in rural areas, and then these particular demonstration programs can provide the technical assistance to the other states as they establish programs later on.

We believe that the Federal Government should investigate ways by which people with disabilities can voluntarily indicate that they desire receiving product information from commercial firms. Well-intended privacy acts have created a barrier to the free flow of information from commercial vendors to people with disabilities who want and need that information.

These individuals should be permitted to participate in deciding their own destiny, and the free flow of information and information exchange can significantly improve this capability. The individuals covered by various Federal support and service programs are ideal candidates for this type of voluntary self-identification.

The Federal Government should, further, provide funding for professional training and public education programs relating to assistive technology. Professional service providers and third-party payment personnel, especially the case managers and claims adjusters must be knowledgeable about the availability and potential of the state-of-the-art assistive technology.

These individuals are often the brokers who stand between the person with the disability and assistive technology that will provide increased independence and productivity. Provision of quality professional training for these individuals will be very cost-effective in the long run.

Federal and state governments must find a just balance between consumer safety on one hand and company and personal expenses associated with liability coverage on the other. The litigious nature of our society is a threat to many small businesses. Many quality companies, small companies, have gone out of business in the assistive technology field in the last few years, especially those that are in the area of medical and motor devices, because of the high cost of liability insurance. We must examine ways of reforming the "joint and several liability doctrine" so that we can have decreased premiums for these very important companies in our field.

The Federal Government can also encourage expansion of commercial involvement in this field by avoiding taking certain action. I will just mention a couple in closing. Government procurement and claims officers should avoid rigid adherence to the use of "low bids" at the cost of product quality and cost benefits of the "best bids."

Experience demonstrates that purchase of the least costly assistive technology frequently demands annual replacement of that device—not very cost beneficial. Federal regulation requiring acceptance of low bids for assistive technology should be suspended for 5 years to provide Government procurement officers the opportunity to gain the expertise necessary and the experience necessary to carry out the appropriate policies of accepting best bids. In the meantime, these procurement officers can call upon experts within the field to be knowledgeable consultants for them.

Also, the Food and Drug Administration provides safeguards against release of inferior or unsafe medical and diagnostic equipment. Unfortunately, FDA's involvement with such equipment as sensory and communications devices often delays the introduction of these devices and increases the prices of these products, while not providing the consumer adequate safeguards because these devices will be safe at the very outset. We believe that technology that does not involve biological measurement or functioning should be exempt from FDA regulations. The current activity of GSA dealing with computer equipment should provide the Federal Government experience in setting standards, functional performance standards for equipment that can carry over into other assistive technology areas, such as sensory and communication devices.

Finally, the Federal Government should not compete with private sector commercial firms in the production and distribution of assistive technology, as proposed in the Rehabilitation Act amendments of 1986 in Section 202(l) that talked in terms of establishing a quasi-governmental corporation to work in this area. That does not seem to be an appropriate way to move. Private industry can provide and will provide this technology on its own as long as the financial demand, the market demand exists.

Mr. Chairman, I was to conclude with a brief statement that I had read into an Optical Character Recognition machine, but if the time does not permit, I will defer my closing and allow you to ask us questions.

Senator HARKIN. I would like to see it. What is it?

Dr. SCADDEN. All right. It's a state-of-the-art reading machine, put out by the Kurzweil Company. I typed a page and it has been read into the machine and, with any luck, just pushing a button, it will operate.

Senator HARKIN. What did you do first?

Dr. SCADDEN. I had a printed page that was scanned by a computer.

[OCR reader audio.]

Senator HARKIN. That was just a printed page; right?

Dr. SCADDEN. That was a printed page that was scanned by a camera, and the optical character recognition capability of the computer, built into this machine, then converted that into a string of data sent to a speech synthesizer. So it is a true reading machine, made available for blind people.

Senator HARKIN. I missed it—my staff told me it was on exhibit yesterday as one of the devices over in the Hart Building. I just missed it. That's pretty remarkable. That is portable, obviously.

Dr. SCADDEN. Yes, it is. It is the state-of-the-art reading machine just recently introduced into the marketplace.

Senator HARKIN. How long does it take to read a paragraph?

Dr. SCADDEN. It's possible to read and listen to it while it's reading, so that you are no more than one or two lines behind what the camera is reading. So it's really in the media time frame as it is reading.

Senator HARKIN. Thank you very much. That was interesting. How much does it cost?

Dr. SCADDEN. With all of the bells and whistles, it will run as high as $12,000. The stripped-down model is still $8,000. That is with a hand-scan camera.

Senator HARKIN. I see.

[The prepared statement of Dr. Scadden follows:]

TESTIMONY FOR THE SENATE SUBCOMMITTEE ON THE HANDICAPPED

BY DR. LARRY SCADDEN

This testimony is offered on behalf of the Assistive Devices Division of the Electronic Industries Association. Division members include the following:

Adaptive Peripherals, Inc.

Apple Computer, Inc.

Applied Concepts Corporation

Artic Technologies

AT&T

ComputAbility Corporation

IBM Corporation

Kurzweil Applied Intelligence

Kurzweil Computer Products, Inc.

NYNEX Corporation

Optelec U.S., Inc.

Phonic Ear, Inc.

Prentke Romich Company

Sonic Alert, Inc.

Street Electronics Corporation

Telesensory Systems, Inc.

VTEK

Williams Sound Corporation

X-10 (USA) Inc.

May 20, 1988

TESTIMONY FOR THE SENATE SUBCOMMITTEE ON THE HANDICAPPED

Mr. Chairman and distinguished members of the Senate Subcommittee on the Handicapped, it is a privilege for me to provide testimony regarding technology and people with disabilities. My name is Lawrence Scadden, and my primary interest in the role of technology for people with disabilities is as a user of assistive devices. I have been totally blind since the age of four, and I can attest to the value of assistive technology. Modern technology is providing me an ever increasing amount of independence and productivity. My career, however, also has been involved with assistive technology, first as a scientist and later as an executive in both the public and private sectors. Currently, I am Director of the Rehabilitation Engineering Center at the Electronic Industries Foundation and serve as staff director for the Assistive Devices Division of the Electronic Industries Association, EIA.

I would like to take this opportunity to present an industry view of the Federal role in improving the development and distribution of assistive technology to people with disabilities.

Industry will provide quality assistive technology and devices for people with disabilities when a financially-based market demand exists. Policies and practices of the Federal government can either promote or hinder industry's participation in this endeavor.

The Federal government can stimulate the market demand for assistive technology through implementation of the following policy recommendations:

First, the Federal government should stimulate the financial capacity of people with disabilities to acquire needed assistive technology. This includes support of policies and programs that serve to enable these individuals to participate financially in the procurement of the technology. Increased personal income acquired through productive gainful employment is the most logical and dignified means to acquire this capacity. Assistive technology can frequently improve competitive job performance, and it is often essential for entry level employment and for upward career mobility. Thus, policies and programs that facilitate the acquisition of assistive technology for employment-related activities are paramount.

The Federal tax code should continue to provide people with disabilities tax deductions for the purchase or lease of technology used in employment. Further, these provisions of the tax code should be extended to cover the cost of educational and training programs and to families of dependents who have disabilities.

Tax considerations should be provided employers who purchase or lease assistive technology for employees who have disabilities. Specifically, passage of Senate Bill 1806 is urged. Rapid recovery of the costs associated with providing essential assistive technology for disabled employees can serve as an incentive to employers. Further considerations should be given to encouraging employers to transfer title of the technology to the individual providing personal use of the technology in other activities of personal life. The government could credit the employer an additional percentage of the cost of the technology for each quarter the individual is employed thus stimulating long-term retention. After two or two-and-a-half years, title would be granted to the user.

Many groups support the establishment of Federal guarantees of commercial loans for people with disabilities to be used for technology acquisition. The disappointing delinquency and default rates experienced with similar educational loan programs elicit caution. The Federal government should initially support innovative, and well-managed, private sector and State demonstration projects to study the feasibility of operating such programs.

Second, the Federal government should stimulate State and local efforts to establish and operate assistive technology support programs. These jurisdictions currently manage most of the Federally supported "transfer of payments"--the vast array of welfare, health care, and employment service programs. An estimated $60 billion is spent annually to maintain people with disabilities in this country. A well conceived and coordinated State program that redirects a small percentage of these funds for the acquisition of assistive technology and the delivery of related technical services--such as personal assessment, training, installation and maintenance--could prove extremely cost effective. Such programs should be encouraged. The Federal government should initiate a competitive State grant program to share the cost of planning and establishing demonstration projects designed to study the effectiveness of the concept and later to provide technical assistance to other jurisdictions. Consideration should be given to creating financially-based rewards for granting continuation of these State grants. Reimbursement of State funds used in operating this program might be provided at levels proportional to achievements in predetermined program performance criteria, such as numbers of people attaining competitive employment status, numbers successfully completing training programs, amount of additional Federal taxes generated by newly employed individuals, or amount of reduced Supplemental Security Income and unemployment benefits required.

Third, the Federal government should investigate ways by which people with disabilities can voluntarily indicate that they desire receiving product information from commercial firms. Well-intended privacy acts have created a barrier to free flow of information from commercial vendors and people with disabilities who want and need information on modern technology. These individuals should be permitted to participate in deciding their own destiny, and free exchange of information can contribute significantly to this end. The individuals who are covered by various Federal support and service programs are candidates for these proposed efforts. Further, the tax code again contains a possible means to encourage large corporate employers to initiate similar programs within their personnel ranks. A modest credit might be offered for each name generated to cover the cost of operating such a internal campaign.

Fourth, the Federal government should provide funding for professional training and public education programs relating to assistive technology. Professional service providers and third-party payment personnel must be knowledgeable about the availability and potential of state-of-the-art assistive technology. These individuals are often the brokers who stand between the person with a disability and the assistive technology that can provide increased independence and productivity. Improving the quality of the decision-making and service delivery activities of these professionals will be cost effective.

These public education and professional training programs should include special efforts designed for the insurance industry. Private insurers, particularly those who carry long-term disability insurance (LTDI) and workers compensation policies, regularly invest in assistive technology. Built-in incentives exist to encourage private carriers to pay for assistive technology that has the potential of expediting injured workers' return to work. Workers comp has historically taken the lead in investing in assistive technology and related rehabilitation services as important benefits. LTDI policies also tend to include rehabilitation provisions. These practices should be anticipated considering that these carriers are frequently faced with major long-term financial commitments. Even high, short-term investments for assistive technology and related services may be cost effective when weighed against long-term client support.

Nevertheless, persons with disabilities frequently cannot obtain insurance coverage for assistive technology and related technical services. The source of this paradox commonly rests with the primary payment decision makers--claims adjustors and case managers who are not up-to-date on what is possible and available in today's technology. The insurance problem,then, may be more a training and information issue than a coverage one.

may be more a training and information issue than a coverage one. The case decision-makers must be more aware of, and familiar with, assistive technology before the cost effective investment can be made.

More financial resources must be directed toward in-service training of case managers and other case decision makers. Similarly, academic institutions that train entry level insurance personnel must develop curricula to teach case level personnel about what is possible, where to get more information about it, and how to make appropriate selection and payment decisions. The private insurance industry already invests in personnel training and information support. Assistive technology must be integrated into the content of these programs so that the insurance industry can improve its process of decision-making regarding cost-effective investment in assistive technology and related services appropriate for individual cases.

Fifth, the Federal and State governments must find a just balance between consumer safety concerns and company and personal expenses associated with liability coverage. The litigious nature of our society is a threat to some small businesses. Within the last four years, I conducted a study of the disincentives to industry participation in the assistive technology field. A number of responses from company officers indicated major concerns regarding the effects of increasing liability insurance premiums. Each of the companies expressing these concerns were involved with either durable medical equipment or mobility products. (Liability coverage does not appear to be a significant issue for the sensory aid and communications equipment manufacturers that I represent today.) One articulate response elicited by the previously mentioned study stated, "I know of new products that are being introduced in other countries, but not in the U.S.; not because of fears of safety or efficacy of the product, but because of fears of frivolous litigation costs and their effect upon liability insurance costs and availability. I would regard this issue as the major disincentive for introduction of new products and the low diffusion of quality products into common usage." Insurance premiums for many companies have risen ten-fold in the past three years; some small but quality companies in the assistive technology field have gone out of business solely because of the high cost of liability insurance. Current legislative efforts aimed at addressing the nation's concerns with abuse of liability coverage should include measures to alleviate the special problems of small business.

The Federal government can also encourage expansion of commercial involvement in the assistive technology field by avoiding other potentially restrictive policies.

First, government procurement and claims officers should avoid rigid adherence to use of "low bids" at the cost of product quality and cost benefits of "best bids." Experience demonstrates that purchase of the least costly assistive technology frequently demands annual replacement. Federal regulations requiring acceptance of lowest bids for assistive technology should be suspended for five years to permit government procurement officers to gain experience with these products and to assess the cost effectiveness of "best bids." Performance and life cycle data must be gathered. In the interim, procurement offices could retain the services of knowledgeable outside consultants to provide objective, expert advice.

Second, although the Food and Drug Administration provides safeguards against release of inferior or unsafe medical and diagnostic equipment, FDA involvement with other products, especially those designed for people with sensory or communication impairments, tends to be costly and inconsistent while not providing value to consumers. Manufacturer activities required to obtain FDA clearances can be expensive and time intensive leading to higher product prices and unneeded delays in product release. Manufacturers of reading machines, for example, have been asked by FDA to demonstrate product safety and efficacy. These are product qualities desired by both manufacturers and the intended consumers, but judgments by FDA for these products cannot be justified. Technology that is not involved with biological measurements or functioning should be exempt from FDA regulations. Establishment of product performance standards by the General Services Administration for procurement and lease of electronic office equipment should provide the government with a model that can be used in the future for sensory and communication devices.

Third, the Federal government should not compete with private sector commercial firms in the production and distribution of assistive technology as proposed for consideration in the Rehabilitation Act Amendments of 1986 as Section 202 (L) of the Rehabilitation Act. Enactment of this provision would create a public or quasi-government corporation to promote the production and distribution of assistive technology. An entity as described would constitute unfair competition to private industry unless its activities were restricted to the important area of one-of-a-kind, or individually customized, products and devices, the so-called "orphan technologies."

Mr. Chairman, millions of other people with disabilities can benefit from assistive technology as I have. Private industry can provide the appropriate products, but quality support services must be made available to the potential users of this technology, and assistance must be available to facilitate acquisition. The primary efforts of the Federal government in the area of assistive technology should be to insure the availability of these support services and to encourage and promote the activities that can best be performed by private industry.

Thank you again for the opportunity to participate in these hearings.

Senator **Harkin**. Dr. Scadden, let me ask you a general question about training. Many witnesses, including yourself, have emphasized the need to ensure training for a wide variety of people; users, families, professionals, et cetera. But you mentioned something else that struck me, and that is the insurance area.

Should we also try to insure, at both the Federal and state levels, insurance company claim examiners, Medicaid and Medicare claims specialists, Social Security determination people, experts, employers, labor union representatives? This whole variety of people also perhaps needs some training, too. Is that what you are saying?

Dr. **Scadden**. Yes. That is, in part what I'm saying. I was really stressing the fact that the professionals who are the gatekeepers for the prescription and purchase of assistive technology; that is both private and public insurance claims adjusters and case managers—they must be up to date on what exists and how it can be very cost-effective to provide this technology. It can eliminate the necessity for long-term payments of benefits to this individual if we can provide increased independence and productivity.

Yes, we do need to ensure that personnel and managers within a job situation, are knowledgeable in it. But we need both in-service and pre-service, college level curricula regarding state-of-the-art assistive technology.

Senator **Harkin**. In fact, I'm going to ask all of you that same question, about training of many different people out there.

Dr. White, how do you see the training issue?

Dr. **White**. Regarding the insurance claims adjusters, the claims reviewers, I think that we would have to start at the top and work down, beginning with the claims managers.

Right now, when a claim comes in that is related to assistive technology, the claims reviewer will automatically deny it because it is not a covered benefit. It's not specifically included in any health insurance policy. So their job is to look for reasons to deny claims rather than reasons to pay claims. The concept that something is going to help in the long run, by decreasing payment from the insurance company, is foreign to that person. It's not their role.

If assistive technology were specifically addressed in the plans and policies, it would be the only way, if you will, to educate the people who review claims.

Senator **Harkin**. Our bill asks the states to look into that specific area.

Dr. **White**. That's right. We believe your bill really touches a lot of different areas, and it touches them well, and we support it.

Senator **Harkin**. Are there any places in there we need to pay any closer attention to, on this training aspect? Does anyone else have any thoughts on what I just mentioned about the training of a broad variety of people out there? Mary Pat?

Ms. **Radabaugh**. Thank you. Yes, I have some thoughts.

I agree with what has been said previously entirely. Some of the instances that we run into, especially with our Discount Program where Easter Seal is trying to work with a client to get the product to him, the maze is there in terms of trying to find the funding.

But, again, what you get into is in the case of a computer becoming the voice for a child who can't communicate any other way, and maybe who can't move anything but blink his eyes, or for a person who had a stroke, who can't do anything but move part of an arm, or for a blind person who needs machines like what Larry just used to read to him; in many cases, those adjusters or those claims processors have no idea that, in fact, it is a prosthetic device. Those are Larry's eyes, if you will, for reading printed matter.

So if they were more familiar with the technology—and it's not an in-depth training; it's more of a knowledge of it. That is why our recommendation for educators and rehab professionals, too, to, as part of certification, be required to understand the technology. Then they wouldn't be as opposed to processing those claims, I believe, because they would understand that, in fact, this child can't go to school or communicate with anyone without this technology.

Senator **Harkin**. Barbara, do you have any comments on the training aspect?

Dr. **Boardman**. Well, following people who have made some very good comments; I would distinguish that training occurs at several different points. You have the training of the professional at professional school. Later you have training that occurs as in-service training and you have training that occurs at certification. It's important, when you think about gearing up for an assistive technology system, that you focus on training at the several levels where training occurs for the various professional gatekeepers.

Specifically, I would say that there is the whole area of informational systems which we tried to address in our testimony. Information systems or very underdeveloped in terms of assistive technology. Anyone who is trying to get information to deliver it to consumers is running into serious barriers at many different levels. Because the information system is, part of the foundation that trained professionals are going to depend on, it needs to be built up as part of training.

Senator **Harkin**. Let me ask another question of the entire panel, and it has to do with cost-effectiveness. It just seems to me that during my time here in Washington over the last 14 years of working in a variety of different Government programs, that we really don't operate in a very cost-effective manner—in a lot of areas. This is just one of them.

It seems that we have made a decision, as a society, that we're going to do certain things, or we're not going to permit certain things to happen. We've made the decision, for example, the problem with the homeless aside, that we're not going to let people out on the streets to beg or die on the streets; that at some point, we will act.

What usually happens is that we act at the last moment and it costs us a lot of money, so it's not very cost-effective. I've seen it in food programs—I've been on the Agriculture Committee for all these years—where we tend to come in at the end when it really costs a lot of money. When we see programs that really help, we underfund them. The WIC Program is one case as an example. Every dollar spent on WIC we know saves $3 downstream. So you would think that we would really promote that kind of program, to save the money later on.

OTA just testified, and one of the other witnesses also mentioned in their testimony that around $60 billion a year is spent on persons with disabilities, but the total cost may be much over $100 billion a year.

What I want to ask is just a generic question. Is this cost-effective? Is assistive technology or technology assistance cost-effective? It's going to cost money; we know that. But will it cost any more than what we're doing right now or will it cost less? How cost-effective is it? Who wants to address this question?

Dr. **Boardman**. I think there's two things I would like to distinguish. One is, you have asked is it going to cost any more than what you're doing now. We are currently attempting to look at these numbers, and they haven't been reviewed.

But I think playing out the scenario of how many people you're likely to get back to work, and what you're paying for those people not to work, and assuming that somewhere in a range between 10 to 50 percent of those people, in fact, get assistive technology and go back into the system, you are talking about taking somewhere around—at a minimum, and very conservatively estimated—3 to 6 percent of your people off of income maintenance programs and putting them into employment, where they're not costing you money.

When considering the costs of the program, you must balance the costs against money that would come back into the system when you provide assistive technology. The sort of money you're talking about bringing into the system might be on the order of somewhere between $100 million and a billion dollars, conservatively estimated. You've got something to gain.

Now, I put that with all the usual OTA caveats about numbers. I also put it with the caveat that you're only talking about bringing disabled people into the system with assistive technology. If you provide your assistive technology in the sort of supportive circumstances—coordinated funding, coordinated delivery systems, supportive training—that will allow it to be effective. If you provide assistive technology in a supportive way you're going to have another program that gives people stuff they don't need.

Senator **Harkin**. Dr. Scadden.

Dr. **Scadden**. Yes. I appreciate the opportunity to respond, as well.

In the area of employment, we can certainly show the cost-effectiveness better than we can in other areas of life. For that reason, I will pass over that one and say, yes, it's definitely cost-effective in the employment area.

But in the medical area, we are seeing continually that if an individual is provided the right kind of technology—in one case, we can talk in terms of shoes for a diabetic that will keep circulation appropriately operating. That can decrease the possibility of later amputation. That becomes an extremely expensive proposition for medical insurance, including Government-run insurance programs, to cover.

A paraplegic or quadriplegic that will develop decubitus ulcers; with the right kind of cushions, we can decrease the hospitalization that will be needed—very often $30,000 at a shot to have surgical intervention. But we have found great reluctance on the part of

Government-sponsored insurance programs to provide the necessary equipment to decrease the possibilities of that ulceration taking place. It's called "avoiding spending money on preventive care."

I consider that to be really an absurd lack of cost-effective behavior. We really need to look in terms of long-term benefits rather than what's going to be the benefits in a single year.

Senator HARKIN. Mr. White.

Dr. WHITE. I believe the key word here is independence; that whether we're talking about children who can then go to school and excel in school and can get positions, can get jobs, go to college and become more productive than they would have otherwise, is one facet. The second facet is the work force. Dr. Boardman addressed that.

I think what we need to key in on here is older people, as well. They're not going to reenter the work force—they may. But when it comes to Medicare, I think the key for independence is older people won't need long-term care, or they will need less long-term care. They can remain independent; they can remain at home; and we know that is much less costly.

Ms. RADABAUGH. I have several examples that really hit close to home on this particular one. First, regarding Larry Scadden's comment; I am a brittle diabetic, and I know your comment about the shoes because I have already lost a toe; but shoes aren't covered today. Fortunately, I can afford to buy the kind of shoes I need.

But I wear an insulin-infusion pump which runs in the neighborhood of $3,000 to $5,000, and when I got my first one, about 7 years ago, it was not covered by any kind of insurance. Today, you can barely find a company that does not cover it. The bottom line to that is, personally, it has cut my hospitalization stays by about 75 percent.

You talk about long-term benefits—I'll talk about short-term benefit also.

Senator HARKIN. That's cost-effective.

Ms. RADABAUGH. Yes. But specifically, also in the job area. One place alone we went to with our Executive Awareness Program, one of the company executives came up to me at the end of the program and said, "We have, today, 300 people out on total disability. We will buy equipment. Will you help us train them? We think we can get most of them back to work?" One example of one 90-minute program.

Another example: I did a customer briefing for a large utility. The CEO of that utility came to me and said, "I heard about your center. Specifically, I'm interested in solutions for people with vision problems and people with mobility problems. Could you show me some?" I did.

Afterwards, he said, "This is the best example of IBM's added value I have ever seen, and let me tell you why. I have been looking for 3 years to find a solution to bring two disabled executives back to work that are on full disability. Both had accidents; one is blind, one is a quadriplegic, and I need their brain power and experience, and I couldn't do it. This technology allows me to do that."

Finally, through the Discount Program, we have example after example of people working on higher education degrees; people like a man who is a quadriplegic, using a sip-and-puff computer to run a business. And the examples go on and on and on.

Senator **Harkin**. Well, we are about ready to leave. I just got notice that we are about to start our roll-call votes.

We are always trying to figure out exactly what the role of the Federal Government should be here. What I have heard all of you, and from the previous panel, says in various ways that there are at least three or four different areas that need to be stimulated: the Federal level, state level, and local and private sectors; and that Federal actions that we take here ought to stimulate all those different areas into some kind of a network, some type of a pulling together, to get this technology assistance out there and to get the training out there.

I am just more convinced than ever, after yesterday and today's hearings, that there's not just one way of doing this. There may be many different ways; and that, we have to permit a system that will allow ingenuity—such as the great things that private companies like IBM have been out there doing—and that allow that system to operate in some kind of a coordinated manner.

Again, we've talked about different options, such as centers—a center might work in one place; but in a rural area, it might not. You've got to have different systems out there. I guess what I am saying, in short, is that we need a systems approach to this. And, again, a systems approach that will be flexible.

Again, we need to convince policy makers that this is a cost-effective way of doing it. There is the feeling among my colleagues in the Senate, and I'm sure in the House, as there is in private industry, that this is something that we as a society ought to do.

While there may be an unwillingness to help the deadbeats in society who, through their own fault or what-not, aren't providing for themselves, no one who I know of, in Government or anywhere, would say that those who are disabled, through no fault of their own, should be left to their own devices; that we as a society ought to provide the support and anything to enhance their lives. That feeling is there.

But the feeling is also there that we've got tremendous budget problems; we just can't do all the good things that we might want to do. So we have to show that it is cost-effective. We have to show that by doing these things, not only do we enhance individuals' lives, but we actually save the taxpayers money in the long run.

I feel that that is so in this case. Money up front for assistive technology may cost a lot of money, but when you look at it, spread over years of additional productivity of an individual, it pays back so much money that, again, in the long run, it becomes much more cost-effective than just taking care of that individual in a very costly, intensive manner later on sometime.

So to the extent that any of you here in the room can provide us with information regarding the cost-effectiveness of this, that would be most helpful in getting this through. We've got to show it for budgetary reasons.

Again, I thank this panel and the previous panel, all of you. It's been a great two days of hearings. I thank all of you who were involved in the demonstration yesterday—I had a lot of senators come up to me last evening, and even this morning at a breakfast, telling me about how much they enjoyed seeing all the new technology. I believe we can get the legislation moving and get something rolling on this fairly rapidly.

Again, I want to thank the staff. I especially want to thank Rud Turnbull, Andrea Solarz, Bobby Silverstein, Katy Ben, Terry Muilenburg, and everyone else who has been more than helpful on this. It's really the staff who has been working on this for so many months to get everything pulled together, not only for the legislation but for the hearings and the display yesterday.

So let's all keep in touch and let's keep the ball rolling on this.

[Additional material submitted for the record follows:]

STATEMENT OF

MADELEINE C. WILL

ASSISTANT SECRETARY FOR SPECIAL EDUCATION

AND REHABILITATIVE SERVICES

U.S. DEPARTMENT OF EDUCATION

HEARING ON ASSISTIVE TECHNOLOGY
FOR PERSONS WITH DISABILITIES

SUBCOMMITTEE ON THE HANDICAPPED

UNITED STATES SENATE

MAY 19-20, 1988

There is a growing appreciation of the role that technological aids and devices can play in increasing the educational opportunities, vocational performance, and quality of life for persons with disabilities. The types and numbers of such devices have increased substantially in recent years. This is particularly true in regard to computer and other electronic equipment, which can dramatically increase the communication and information-processing abilities of persons with disabilities. Technological aids may also be used to provide greatly increased mobility and environmental control for severely physically disabled persons, enabling them to engage in a broader range of activities.

Each of the three major OSERS program components supports activities in technology. Under the vocational rehabilitation program, State rehabilitation agencies provide a wide range of technological aids and devices to disabled persons to assist them in becoming employed. Since 1986, State agencies have been required to provide rehabilitation engineering services, if appropriate, to all clients. The special education program supports project grants to advance the use of new technology, media, and materials to assist in educating and providing related services to children with handicaps. The National Institute on Disability and Rehabilitation Research funds rehabilitation engineering centers and supports selected project grants related to technology research and utilization.

Technological aids for disabled persons need not be expensive or complicated. Many disabled persons can benefit greatly from simple, straightforward, often inexpensive equipment or modifications to their personal environment or worksites. Examples of this are relocated or adapted electrical or mechanical controls and sensors, and simple jigs or fixtures to assist in holding or positioning items necessary for work or daily living. However, the evaluation of a disabled person's technology needs, the determination of an appropriate and cost-effective technological solution, and the purchase, or design and fabrication, of the technological device is complex and requires a high degree of specialized knowledge and skill. Simple solutions are sometimes arrived at only after the consideration of many interrelated human, technical, administrative, or financial factors. Yet these factors are often not easily managed or coordinated to ensure that the right technology is available and delivered to the handicapped individual.

More specifically, the provision of technology to persons with handicaps is currently characterized by a fragmented service delivery system in which the purchase of technology, the delivery of technology, and information about technology are not integrated into a mutually reinforcing and complementary whole. Rather, a very inefficient, uncoordinated approach to the provision of technology exists. For example, medical providers may prescribe and pay for an assistive device for an individual, but the device may not be usable or compatible with the vocational, educational, or independent living needs of the same client, although such a compatible device may exist. In addition, the funding requirements for the purchase of technology from sources that are reimbursed by health insurance funds may result in incomplete or inappropriate services being delivered. Under the present system of medical reimbursement, moving a client from the bedroom to the bathroom may be of paramount importance and devices to do this can be provided. The client's real need, however, may be to be able to move to and from, and work comfortably at, a home computer workstation. Yet, expenditures for these work-related devices may not be covered. Similarly, devices for mobility may be provided without regard to their potential usefulness and appropriateness in meeting an individual's work-related travel needs. Because technological aids provided through health insurance sources are oriented toward remedying needs directly related to medical care, the vocational, social, educational, and other long-term client needs are often either not considered or are judged not relevant to satisfying the objectives of the medical care system.

The problem of fragmentation is further illustrated by the provision of advanced technical equipment such as communications aids, environmental control systems, and information processing devices. This equipment needs to be planned for and provided on a systematic basis to avoid the problems, well known to users of small computers and their peripherals, in which two or more devices purchased separately will not work together. Planning for compatibility in these cases is difficult, if not impossible, to achieve. The result is that the disabled user ends up with devices that will not work together, resulting in the need to purchase additional technology that is compatible.

There is also a lack of information about programs and funding sources for technology because of the wide range of potential payors and the lack of personnel who are familiar with the various programs and their requirements. Technical knowledge of products and solutions must be utilized in combination with program and financial information to provide and pay for devices in an efficient and logical manner. The recent growth of the rehabilitation engineering area has, in many cases, outpaced the commonly available knowledge about these technological solutions and how to evaluate and fund them.

To begin addressing the problems that are outlined, last year I formed a Task Force on Rehabilitation Engineering composed of representatives of major public and private providers and consumers of rehabilitation technology. The Task Force has been extremely helpful to the rehabilitation engineering community. It will collect, produce, and disseminate information on rehabilitation engineering services. To date, the Task Force has conducted a survey on the delivery systems for rehabilitation engineering services and prepared discussion papers on sources of financing rehabilitation engineering services, service systems, and the provision of rehabilitation engineering services by State vocational rehabilitation agencies. I also anticipate that it will serve as a focal point for collecting information from outside organizations on a variety of issues, which may include financing, model service systems, and technology development in the State-Federal vocational rehabilitation system.

As one strategy to develop a more integrated and coordinated system to ensure the effective delivery of technology to handicapped individuals, I am planning a new initiative. Specifically, in FY 1989 I am planning to use RSA special demonstration or NIDRR demonstration authority to fund grants to support State development efforts to achieve a statewide comprehensive approach to delivering technological goods and services to persons with handicaps. These grants would be designed to identify gaps in services and develop strategies for filling them, and to develop the potential of existing service systems to provide cost-effective solutions to the problems created by disabling conditions. The conceptual model for these grants would be the "Statewide change" demonstration grants for supported employment. The project period for these grants would be five years. These grants would be specifically focused on:

- The development of technology providers, provider roles, and standards that are applied to providers to evaluate the quality and effectiveness of services;

- The development of information concerning the availability and uses of technological devices and the development of model systems to procure devices;

- The provision of education and public awareness activities;

- The provision of professional training and resource development;

- The examination of State education, rehabilitation, health, and insurance regulations, policies, and programs to identify and eliminate barriers to delivering technology and technology services in a comprehensive and coordinated fashion;

- The conduct of State technology needs assessments;

- The trial use of innovative methods, such as equipment loan programs, of making technology available; and

- The identification and coordination of State and local financing and reimbursement mechanisms for the provision of technology services.

I believe that this program of grants for Statewide change in delivering technology will begin to address the problems in the service delivery system that I have identified. This program should focus the attention of State policymakers on the opportunities that rehabilitation technology can provide and on the desirability of developing improved systems of service. The activities that these programs would support are the critical elements of an improved approach to the delivery of services and the success of these efforts could then be described to additional States through a vigorous outreach process.

I assure the members of this subcommittee that I have established the improvement of technology services to disabled individuals as one of the highest priorities of my office and am willing to work with members of the subcommittee to achieve this objective.

The Power To Overcome

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STATEMENT

submitted by

THE NATIONAL EASTER SEAL SOCIETY

to the

SUBCOMMITTEE ON THE HANDICAPPED

SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES

regarding the May 19-20, 1988

Hearings on Assistive Technology

June 6, 1988

We are submitting this statement in connection with the hearings on assistive technology which were held May 19-20, 1988. We request that these comments be included in the hearing record.

The following is intended as an overview of Easter Seal activities relating to assistive technology programs and services. Easter Seal programs are as diverse as the communities they serve. The programs described in this statement were selected to illustrate the range of technology services available through Easter Seals and common barriers encountered in the delivery of those services.

The National Easter Seal Society, founded in 1919, is the nation's oldest, nonprofit voluntary health agency providing direct services to people with disabilities. Easter Seals serves over one million people annually through 400 program sites in all 50 states, the District of Columbia and Puerto Rico.

Easter Seals serves people of all ages and disabilities. Easter Seal programs provide a broad range of services that include physical, occupational, and speech language therapies, vocational evaluation and training, camping and recreation, psychological counseling, screening programs for potentially disabling conditions, information and referral, and family and community education. Technology assistance is an integral part of the comprehensive services provided by Easter Seals.

Service fees are based on the client's ability to pay. No one is refused services because of financial limitations. Financial support for Easter Seal programs comes from a variety of sources, including contributions from individuals and corporations, legacies, special gifts, fees, grants, contracts and bequests. Easter Seals must rely on public contributions to cover program costs for those clients who cannot pay the full costs entailed.

The National Easter Seal Society has taken a leadership role in the utilization of technology to help people with disabilities achieve the maximum independence possible. RESNA, the Association for the Advancement of Rehabilitation Technology has named the National Easter Seal Society as this year's recipient of its Leadership Award. The award recognizes the Society's "outstanding contribution and on-going leadership in the field of technology applied to needs of disabled individuals."

Nationally, Easter Seal partnerships with the private sector, information dissemination efforts and research activities have focused on the technology needs of people with disabilities. On a local level, Easter Seal affiliates provide technology assistance through a community based approach that draws on local resources and expertise. The programs involve close coordination with state agencies and community organizations.

I. PRIVATE SECTOR PARTNERSHIPS

The National Society believes that partnerships with the private sector should be encouraged and promoted. We have been involved in a number of cooperative ventures with the private sector over the years.

Some of the benefits resulting from these projects include 1) an increase in the number of people with disabilities having access to assistive devices; and, 2) an opportunity for the private sector firms to highlight their corporate commitment to people with disabilities and to heighten public awareness of the adaptive technologies available to them. An increase in public awareness helps to strengthen market demand for these products.

EASTER SEAL/IBM ASSISTIVE TECHNOLOGY PROJECT

In September 1987, Easter Seals and IBM announced the IBM Offering for Persons with Disabilities. The joint project was created to provide computer products and assistive devices to people with disabilities at discount prices. The National Easter Seal Society was selected as the community service organization for this offering.

To become eligible for the program, an individual must submit a letter from a licensed physician stating that the individual has a disability and would receive therapeutic or rehabilitative benefit through the use of one or more of the products available in the offering.

The letter of certification is sent to the nearest Assistive Technology Center. These centers are operated by Easter Seal affiliates. There are currently ten centers located in Arkansas, California, Colorado, Florida, Georgia, Illinois, New Jersey, Rhode Island, Texas and Utah.

Each Assistive Technology Center provides the following services:

1) hands-on demonstration and evaluation of available products;
2) assistance in choosing products, calculating payment and filling out the appropriate order forms;
3) receipt, assembly and testing of systems to ensure that products are operational prior to delivery to the end user;
4) discussion of warranty and maintenance options available to the end user and procedures for obtaining them;
5) hardware set-up assistance and initial training; and,
6) telephone support for on-going assistance once the system has been delivered to the end user.

The equipment is available for purchase at a 33-50% discount.

Despite the significant savings provided through the IBM Offering, financing equipment purchases is very difficult for eligible individuals. Even with the discount, the equipment costs range from about $300 to $2,000. To date, there are no programs that would provide low interest, variable term loans to people with disabilities for the purpose of obtaining assistive technologies and related services.

Financial institutions are reluctant to finance equipment purchases and are not likely to approve loan applications from individuals who do not have an established credit rating. Requiring a lump sum payment for equipment places a financial burden on those with limited resources.

Exploring reimbursement sources for assistive technology devices requires a significant commitment of staff time and effort. For example, the New Jersey Easter Seal Society operates an Assistive Technology Center that serves New Jersey, New York, Connecticut, Pennsylvania, Delaware, Maryland and the District of Columbia.

Part of the technical support involves sorting through reimbursement policies for state vocational rehabilitation agencies, Medicaid programs, private insurers and other third party payors. The staff must deal with over 21 different Medicaid systems in New Jersey alone. Another problem in coordinating payments is reluctance on the part of some state agencies to pay the state tax required for purchase of the IBM equipment.

Unless creative solutions are found to help with the financing of equipment purchases, the market will continue to be limited to those who can afford lump sum payments or those who have found a charity or other source willing to assume out-of-pocket costs for the equipment.

Other Cooperative Ventures

Five years ago, Apple Computers donated 400 used computers to the National Easter Seal Society. The National Society spent about $35,000 to store, test and refurbish the computers, which were then made available to Easter Seal affiliates.

The New Jersey Easter Seal Society uses the Apple computers in training centers for people with developmental disabilities. Individualized computer programs have been created that correspond with the person's Individual Habilitation Plan.

AT&T provided $10,000 to underwrite an issue of COMPUTER DISABILITY NEWS. The newsletter is published by the National Easter Seal Society and is widely read by special educators and service providers interested in assistive technology. Newsletters and other publications are a major source of technology assistance to both consumers and service providers.

On a state level, the Connecticut Easter Seal Society operates a computer camp that is affiliated with Newington Children's Hospital. A professor from the University of Connecticut directs the program, and the University provides staff and equipment for the two-week camp. Newington Children's Hospital provides financial assistance for the camp, which serves children 10 to 17 years old. Computer terminals are modified to meet the individual needs of the campers.

The camp itself is a model for accessibility: the building was designed without stairs, and there is an accessible stage and other special features such as plumbing gauges to prevent scalding. The Connecticut Easter Seals also developed a networking system so that the participants will continue to develop their skills once they leave the camp.

II. COMMUNITY BASED PROGRAMS

The National Easter Seal Society believes that community based service delivery is an effective approach for meeting the needs of people with disabilities. Easter Seal programs provide technical assistance to underserved populations in rural as well as urban settings. A critical component of the community based approach involves cooperative agreements and service coordination with state social service and local education agencies.

Serving the Rural Community

There are over 8.5 million people with disabilities in rural areas, including approximately 560,000 farmers and agricultural workers. Currently, there are three major programs in the United States that specialize in rural rehabilitation technology: the Rural and Farm Family Vocational Rehabilitation Program in Vermont, Breaking New Ground at Purdue University in Indiana, and the Iowa Easter Seal Society's Farm Family Rehabilitation Management Program (FaRM).

The Iowa FaRM program has been a pioneer in the community based approach to rural rehabilitation technologies. The program director travels many miles across the state to provide on-site agricultural worksite modifications and consultations. Other program features include coordination of independent living and community services, use of community resources in the design and fabrication of adaptive devices, peer support services, and ongoing communications between the family and health care providers.

The program director is currently carrying a case load of over 140 families. Additional resources will be critical to the future of the program. Funds for staff training are essential due to the specialized training needed to effectively serve farm families. Without additional trained staff, it will be nearly impossible for the program to expand at its present rate.

The Easter Seal Society of Utah is using another approach to provide services to rural communities. The Utah Society has developed a pilot program using EDNET, a state-owned audio and video microwave system that connects nine regional communication networks throughout the State of Utah. This network enables trained therapists to interact with individuals in rural areas, and saves considerable time and travel expenses. The Utah Society believes that this is a cost effective system for providing program assistance to underserved areas.

The pilot study involved a preschool child with cerebral palsy who needed an augmentative communication device. The child lives in a town that does not have a trained specialist available to assist her with the device. After ten therapy sessions using the EDNET system, the child progressed from having no expressive communication to being able to use 25 phrases that were prestored in the communication board.

The Utah Department of Health is interested in using the system for an infant stimulation program, but currently lacks the funds to implement the program. The Utah Easter Seal Society is seeking private and public funds that would make it possible to continue the pilot project and to develop additional training modules for the program.

Coordination with State Agencies

The Massachusetts Easter Seals' PROJECT TECH provides comprehensive technology assistance to people with severe disabilities, including individuals with augmentative communication needs. The program is partially funded through the Massachusetts Rehabilitation Commission. Individuals are referred to the program through the Commission and other sources, including schools, hospitals and social service agencies.

PROJECT TECH provides linkages with local resources. It depends on a team of highly skilled professionals in speech therapy, physical and occupational therapy, rehabilitation engineering, computer hardware and software, vocational rehabilitation counseling and the full spectrum of assistive technology. The Easter Seal Tech Team offers evaluation, assessment and recommendations for assistive technology. Easter Seals' professional staff provides training, follow-up and assistance with securing equipment. Whenever possible, consumers are linked with volunteers in their own communities for continuing support, information and training.

The Texas Easter Seal Society recently purchased a driving simulator that is used to test reaction time and responses to complex situations of individuals with traumatic head injuries. The simulator was purchased at a cost of about $37,000. It took over a year to raise funds for the purchase.

The Texas Rehabilitation Commission and other state agencies are now referring clients to the Texas Easter Seal Society for testing and evaluation. The Texas Easter Seals is also using the simulator to test adaptive equipment. Testing and evaluation are conducted on a fee-for-service basis.

The Texas Easter Seal Society will recover the cost of the simulator within three years. State agencies have avoided costly purchases by coordinating services with Easter Seals. However, in order to meet the rehabilitation technology needs of other Texas residents with disabilities, the Texas Easter Seal Society will need to raise an additional $360,000 for equipment purchases. Flexible, long-term financing programs would help expedite the process of buying this equipment.

Despite the success of these programs, signficant barriers remain that affect service coordination. For example, the Illinois Easter Seal Society operates a comprehensive outpatient rehabilitation facility. Services include foster care, respite care, home health services, prosthetic/orthotic clinics and support groups.

In one case, an institution refused to release a child into foster care because there were no funds available to purchase a powered wheelchair for the child. Although the foster home had ramps, the child lacked the strength to maneuver a manual wheelchair and required a powered model for mobility. In other cases, a state agency took so long to process requests for wheelchairs that, by the time the wheelchairs arrived, the children had outgrown them. Devices and services falling outside the "durable medical equipment" category are routinely denied by the agencies.

III. INFORMATION DISSEMINATION

Another major barrier to service delivery is a lack of information and awareness of assistive technology services. This is particularly true for rural areas. The National Society strongly supports efforts to coordinate and disseminate information on assistive technology services for both consumers and service providers. We continue to promote research in this area.

Rehabilitation Technology Volunteer Census Project

The Easter Seal Research Foundation, established in 1956, is the research arm of the National Easter Seal Society. Grants funded by the Foundation support research relating to the development and use of technology.

The Foundation recently awarded a grant to identify voluntary groups working in the field of rehabilitation technology. The nationwide study will provide a census of groups and individuals working on a volunteer basis and will consider ways in which the volunteers can help each other. This research is providing the first step in establishing a nationwide network for sharing resources and designs that would benefit people with disabilities.

Jim Tobias, founder of the Rehabilitation Engineering Volunteer Network, is directing the project. Following completion of the census next year, some long-term goals for the project include:

* creation of a "design file" that would contain information on completed projects to encourage problem solving and information sharing among engineers

* establishment of a center for collecting and storing surplus equipment that could be made available at a discount to people with disabilities

* development of a program for resource sharing of training materials developed by various groups involved in the delivery of assistive technology services

Additional funding would be needed before these and other ideas could be developed. However, the intial study will provide a research base for developing technology information and referral systems on both national and local levels.

IV. OTHER CONSIDERATIONS

The National Society believes that a system for technology assistance should provide for successful transitions throughout the lives of people with disabilities. This requires an increase in funding commitment for specialized training of personnel, and policies for developing professional standards for service delivery. Reimbursement policies must be studied to 1) determine priorities for funding technology assistance; 2) ensure that individuals are reimbursed as they make the transition from one system to another; and, 3) ensure that individuals defined as handicapped or disabled under federal or state law are reimbursed for technology assistance that enables them to achieve life activities. Barriers to service delivery must be identified and eliminated.

For example, the New Hampshire-Vermont Easter Seal Foundation is finding that private insurers are routinely denying reimbursement of services to individuals with developmental disabilities. The insurers refuse to pay for services that they claim are "habilitative" rather than "rehabilitative."

Some youths with disabilities require vocational training while in school. In many.cases, students are not reimbursed for equipment purchases unless it is written into their IEP. Some of the school districts are reluctant to fund equipment that they consider to be "work related." The state vocational rehabilitation agency will not fund equipment for individuals who are still enrolled in school. Furthermore, many vocational rehabilitation agencies are reluctant to use limited funds for purchasing equipment for their own clients.

The New Hampshire Easter Seal Society finds it difficult to recruit and retain trained professionals for their employment programs. Trained staffs are needed to develop program plans and to provide the appropriate supervision necessary for successful outcomes. Staff members are often "lured away" by offers from private firms in which they are placed as job coaches. Long-term employment support services are difficult to maintain with the chronic shortage of trained personnel.

V. SUMMARY OF RECOMMENDATIONS

Based on our experience in providing assistive technology services, we recommend that assistive technology legislation should:

1) ensure that technology assistance is an integral part of the comprehensive rehabilitation and independent living services provided for people with disabilities

2) adopt a broad definition of assistive technology that includes related services involved in making an assistive device available to people with disabilities (e.g., information and referral, evaluation, training, technical support, maintenance and upgrading of equipment)

3) require that states conduct statewide surveys of existing programs - both public and private - and use part of the available funds to enhance these programs (this will ensure that the number of people receiving direct services will increase at the same time that states are building their capacity for a statewide assistive technology delivery system)

4) encourage a community based approach to service delivery with citizen/family involvement in the development and delivery of services

5) encourage the development of public/private partnerships

6) establish a funding commission to study existing reimbursement sources and develop programs for financing adaptive equipment and services

7) mandate a short-term study to develop a national program for meeting the technology information needs of consumers and providers

8) provide for a comprehensive system for personnel training

9) address technology needs of individuals who are involved in the transition to another delivery system or developmental stage

10) develop a state grant program that would encourage the creation/expansion of model programs and coordination of services

We commend Chairman Harkin and the members of the Subcommittee on the Handicapped for addressing this critical issue, and appreciate the opportunity to submit this statement for the record.

June 1, 1988

Testimony of

APPLE COMPUTER INC.
OFFICE OF SPECIAL EDUCATION
and the
NATIONAL SPECIAL EDUCATION ALLIANCE
before the
U.S. SENATE
COMMITTEE ON LABOR AND HUMAN RESOURCES
on
Technology-Related Assistance for Persons with Disabilities

Statement submitted by

James Johnson
Director of Government Affairs
Apple Computer, Inc.

NEED FOR FEDERAL LEGISLATION

It is estimated that nearly 4.5 million American children with disabilities could benefit from legislation which would create easier access to adaptive technology. When this figure is increased by the numbers of adults with disabilities and the numbers of parents, educators, and employers who may benefit from the increased independence of the children and adults with disabilities, the importance of legislation becomes greatly magnified.

Never before has one educational tool, the microcomputer, been so useful for providing so many individually meaningful applications for learning, communication, work, and daily life. For individuals with disabilities, the personal applications of microcomputer technology are even more numerous than for the nondisabled population. These allow for such heretofore inaccessible activities as reading the daily newspaper, composition and proofing of written documents, communication by nonverbal individuals, and access to vast quantities of materials stored electronically.

For individuals with severe disabilities, the microcomputer has extremely important implications for communication with a nondisabled world. It can make education very personal. It can rehabilitate and provide a transition into the world of work. For many individuals with disabilities, microcomputer technology holds the only key to their communication, education, and/or rehabilitation needs.

APPLE COMPUTER, INC. OFFICE OF SPECIAL EDUCATION ROLE AND COMMITMENT

Apple Computer, Inc. established its Office of Special Education in 1985 to address the needs of the disabled community. Apple's Office of Special Education provides awareness of the possibilities offered by technology-related assistance, promotes greater accessibility through built-in microcomputer options, and provides resources and information to individuals with disabilities, their families, and supporting professionals. Apple provides information about the broad range of solutions that exists and demonstrates how to use these various solutions at home, work, and school. The corporate commitment by Apple Computer, Inc. toward the advancement of technology for use by individuals with disabilities is powerful, enduring and passionate.

Apple supports the Congress in its efforts to make technology accessible to individuals with disabilities. The impact of such a program is monumental and will change the lives of individuals with disabilities. It will also change our society's view of disability.

Apple also shares information by using electronic resources to accelerate the adoption of computers into the lives of individuals with disabilities. Apple's Solutions Database contains information on third-party products and resources that customize Apple computers to the needs of disabled children and adults. The Solutions Database provides an enormous capacity to identify the sources of specialized software and adaptive peripherals, support organizations and publications. The Database contains information on more than 1,200 hardware and software products, organizations, and publications that support disabled computer users. It is an important information tool for software developers, service agencies, employers, school and university personnel, Apple dealers, and Apple employees. The Solutions Database is also available in a hard-copy version called Apple Computer Resources in Special Education and Rehabilitation. Apple maintains a 24-hour-a-day electronic drop-in center on SpecialNet, a nationwide telecommunications system for special education teachers and administrators.

Apple has a certified developer program that enables developers to receive current product information, technical assistance, and price reductions on microcomputer equipment. Apple's Office of Special Education also assists hardware and software developers by providing information on how to develop and market specialized hardware and software products for the disabled consumer. Apple puts developers in touch with organizations and resources that are specifically designed to address the needs of disabled computer users.

Apple develops hardware which is more accessible to individuals with disabilities. For example, the control panel on the Macintosh and the Apple IIGS computers enables persons with limited mobility to turn off the repeat key function. Close View, another option in the Macintosh control panel, enables a visually impaired person to magnify the screen up to 16 times the normal size. In addition, when the volume is turned off from the control panel of the Macintosh computer, visual clues are provided, thus enabling a deaf person to see the clues rather than miss the audible system beeps. There are Easy Access options built into the operating system for each Macintosh computer that enable a person with limited mobility to operate the mouse from the keyboard or push several keys in a sequence producing the effect of striking several keys simultaneously. These options are available to all users of these computers at no extra charge. Apple publishes a report card on accessible features of all Apple computers. This report is generated for public dissemination and to support on-going recommendations to internal developers regarding additional accessibility features that will support more disabled users.

THE NATIONAL SPECIAL EDUCATION ALLIANCE DESCRIPTION AND GOALS

The development of new technology solutions is occurring so rapidly that individuals with disabilities, their parents and professionals find it difficult to keep up with the new possibilities. Service agencies need up-to-date information on technology to invest their limited resources wisely. Parents and individuals with disabilities often feel that professionals ignore or speak condescendingly to them. On the other hand, professionals often feel that they are being inappropriately challenged or criticized by parents. As new technical ideas and solutions become more prominent in the treatment of individuals with disabilities, it is imperative that we develop different ways for these groups to work together. Apple believes that there is an abundance of information and support to disseminate. To make sure that information and resources are available when and where they are needed, Apple established in 1987 the National Special Education Alliance (NSEA).

The Alliance was initiated by Apple Computer's Office of Special Education in cooperation with the Disabled Children's Computer Group (DCCG). The DCCG is a community-based resource center with a membership of 1,200 parents, teachers, and individuals with disabilities. If offers a wide array of programs and services, and serves as the model resource center for all NSEA resource centers.

The Alliance brings together a core of established organizations dedicated to providing community-based resources to help individuals with disabilities benefit from technology-related assistance in school, at home, on the job, and in the community. The NSEA resource centers are composed of parents of disabled children and disabled consumers working cooperatively with school and university personnel, professional organizations, community leaders and technology vendors. The current 23 NSEA resource centers help individuals discover working partners, ensure timely sharing of information, and serve the computer-related needs of disabled persons.

Simply stated, the goal of the Alliance is to increase awareness, understanding and implementation of microcomputer technology. It is an organization whose members share a common vision and an uncommon commitment to improving the quality of life for children and adults with disabilities. Underlying this goal is the compelling belief that microcomputers are changing what it means to be disabled.

Each center is electronically linked to every other center as well as to major national data bases and bulletin boards via electronic communications networks. This enables each NSEA center to request information regarding specific needs or equipment and receive feedback within minutes or, at least, within 24 hours.

The strength of the Alliance lies in its grassroots orientation. Each resource center is led as much by parents and individuals with disabilities as by professionals. Each center, as a non-profit agency, is autonomous and assumes independent responsibility for sustaining the growth of its local programs and for contributing to the national mission of the Alliance. All NSEA resource centers are committed to establishing a program of activities and events to educate their community about what computers make possible for disabled children and adults. The NSEA resource centers work closely with hardware and software developers to conduct training workshops and product fairs, to make presentations at disability-related conferences and meetings, and to provide valuable community connections and resources. NSEA personnel keep abreast of current developments in technology-related assistance so that they can pass along the most appropriate and up-to-date advice. NSEA activities also include individual consultations and the sharing of resources, tips, and techniques that benefit the disabled computer user. The technology vendors and professional organizations that are members of the NSEA enthusiastically support the NSEA centers with technical assistance, updated information, and, in selected instances, discount purchasing and equipment loaner programs.

LEGISLATION ISSUES TO BE ADDRESSED

Computer technology touches all of us either directly or indirectly in many dynamic ways. Microcomputers have created totally new approaches to meeting the needs of individuals with disabilities.

Most non-disabled individuals, however, are still unaware of the crucial benefits and applications of technology for disabled children and adults. Increased awareness of technology available for citizens with disabilities should be a goal of any new federal legislation.

Some critical questions must be asked. What is accessible technology? What are the current barriers to technological access? What systems, organizations, and structures are currently in place to provide access? How do parents, consumers, educators, and other professionals perceive the current state of access to technology? How can truly barrier-free access to technology be achieved? What is already being done to expedite access to the new technologies nationally? How can Congress encourage and expedite access to barrier-free technology?

Concern for equity cuts across many of these questions and is a central issue in barrier-free technology. Often, the people who should benefit most from adaptive technology are the people who can least afford it. Many children and adults with disabilities are blocked from accessing useful technology in their communities because they belong to the wrong age group, disability group, socioeconomic group or educational services group. Presently, most agency-based adaptive device resource centers are not in a position to adopt a policy of serving everyone, nor are they in a position to assist individuals in obtaining low-cost technology for personal, around-the-clock use.

RECOMMENDATIONS FOR LEGISLATION

We believe that the inter-disciplinary, cooperative approach characteristic of the NSEA is a critical component in any comprehensive adaptive technology legislation. We believe that the NSEA model takes advantage of systems, organizations, and structures that are currently in place, and introduces new technology and information on a daily basis. The model of the NSEA is especially intriguing because it represents both a healthy partnership between the public and private sectors and a community-based, collaborative approach for getting everybody to work together. Moreover, each community resource center is part of a nationwide communications, information, and service network.

The legislation should support and encourage the active participation of parents,

consumers, professionals, government agencies, and vendors. We believe that to provide the vast amount of resources, training and support necessary to implement such a large-scale technology effort, resources will be needed from both public and private sector participants working together.

To ensure success, we believe that the active involvement of disabled consumers and parents of disabled children is imperative. The distribution of funding must be done through a mechanism that will encourage active leadership on the part of disabled consumers and parents of disabled children.

Apple supports a tax incentive for third party vendors who develop adaptive devices, peripherals, hardware and software for the disabled technology user. We believe that a tax credit which is more substantial for smaller vendors than larger corporations would have a positive effect on many of these small, third party vendors, resulting in benefits to the disabled technology user.

Any plan for the distribution of funds must address a mechanism that can support all age groups and all disability areas. When adaptive equipment is individually tailored, it does not make sense to force the disabled person to reapply for the same technology through a different public sector channel at each stage of his or her life. Congress should provide incentives and standards for an integrated system of services and support throughout the life span of the disabled person. The model for receiving services should be the same for individuals with different disabilities. This service model should also be fiscally flexible enough to the meet changing needs of individuals as they progress through their lives and support the best match of technology as it evolves.

It is important to establish an efficient funding mechanism, one which provides the most direct passage of funds from the federal government to local community resource centers.

We firmly believe that a program which provides loaned, free or reduced priced equipment; assists consumers in seeking public and private funding; or enables individuals with disabilities to qualify for a low cost or subsidized loan program is necessary for equity and should be a substantial part of this legislation.

The legislation should include support for the development of training programs for parents, disabled consumers, educators, vocational rehabilitation counselors and other service providers. The grass-roots resource centers such as the NSEA centers would benefit from comprehensive and on-going training modules for themselves and for the individuals with disabilities, parents and professionals they serve. Start-up training and on-going training can be made available (and should be supported by this legislation) through community-based or state resources with the assistance of developers and vendors. Special grants and other support to college/university training programs in the field of special education, computer science, rehabilitation, engineering and other associated fields should be considered.

The National Special Education Alliance has provided an effective model that provides information and access to disabled technology users. We believe a model that supports community-based centers similar to the NSEA model would meet many objectives of the proposed technology legislation and most of the needs of the individuals with disabilities for whom the legislation is designed. Twenty-three Apple-supported NSEA resource centers are now in place with plans to include centers in all 50 states within a year. Each of those centers is built on the belief that consumers and their families, with solid information and accessible guidance and support, can and must make their own life decisions.

Apple Computer, Inc. and National Special Education Alliance are firm in their conviction that monumental access is provided by helpful technology devices. We believe that the legislation should address all technology-related assistance devices, not just microcomputers alone. Apple Computer, Inc. and the members of the National Special Education Alliance believe that individuals with disabilities and their families, once informed about what is possible, will have a powerful role in changing and building their own future.

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NATIONAL MULTIPLE SCLEROSIS SOCIETY

BEFORE THE

SENATE LABOR AND HUMAN RESOURCES
SUBCOMMITTEE ON THE HANDICAPPED

THE HONORABLE TOM HARKIN, CHAIRMAN

HEARING ON S.1586 THE TECHNOLOGY TO EDUCATE
CHILDREN WITH HANDICAPS ACT OF 1988

on

May 19, 1988

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.

Mr. Chairman and members of the Subcommittee on the Handicapped of the Labor and Human Resources Committee, I am John P. Donnelly, Vice President, Public Affairs of the National Multiple Sclerosis Society. I thank the committee for the opportunity to submit testimony on behalf of our 400,000 members.

The National Multiple Sclerosis Society commends Senator Kerry for the introduction of S.1586 the "Technology To Educate Children With Handicaps Act."

It is our hope, however, that in its deliberations the committee will consider the need to expand the scope of this legislation to include Americans of all ages who are handicapped and would benefit by the establishment of assistive device resource centers in each state. There are an estimated 35 million disabled Americans, including at least 250,000 adults with multiple sclerosis -- a disabling disease of the central nervous system for which there is no known cause or cure.

In 1986 the National Multiple Sclerosis Society moved in a new direction -- to supplement our traditional programs of basic and clinical research by providing a means of funding projects aimed at new technologies to help people with MS manage their disease.

The intention is to fund projects aimed at improving function and day-to-day life for people with MS in such areas as psychosocial function, assistive devices and symptomatic treatment. It is well recognized that such areas -- broadly defined in the area of neurorehabilitation -- must be an essential part of a comprehensive program of multiple sclerosis research.

To date the Society has peer reviewed 11 proposals in this new area and funds programs in management of urinary problems in MS, treatment of spasticity, and improvement of cognitive function. The program is very new and we are confident that once the word gets out that such a program exists we will receive considerably more demand for funds from physicians, biomedical engineers, neuropsychologists and others interested in the management and rehabilitation of the handicapped.

As a side light, at a recent meeting of the American Academy of Neurology, a special session in neurorehabilitation drew attention to the fact that physicians not traditionally involved with such matters are becoming increasingly aware of the need for assistive devices and technology for disabled Americans.

Since 1946 the National Multiple Sclerosis Society has been dedicated to support of research aimed at understanding more about MS and developing a means to prevent, arrest or cure the disease. Traditionally this research has been in the area of basic biomedical research and clinical studies to develop new therapies for MS. To date the Society has spent nearly $120 million and is currently allocating $7.6 million dollars annually on such research. While we recognize the importance and the need for the development of patient-management technology, resources of the Society are necessarily limited and many demands are made on us. We believe that expanding the scope of Senator Kerry's bill to include service to all people with handicaps will do much to improve the productive life style and independent living not only of people with multiple sclerosis but all Americans with disabilities.

RESNA Association for the Advancement of Rehabilitation Technology

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STATEMENT

OF

RESNA,

ASSOCIATION FOR THE ADVANCEMENT OF REHABILITATION TECHNOLOGY

ON

ASSISTIVE TECHNOLOGY FOR PEOPLE WITH DISABILITIES

TO THE

SENATE LABOR AND HUMAN RESOURCES COMMITTEE,

SUBCOMMITTEE ON THE HANDICAPPED

MAY 19, 1988

1. Introduction
2. Association for the Advancement of Rehabilitation Technology
3. The Urgent Need for Quality Assurance
4. The Need for a National Study on Certification
5. The Need for Training/Personnel Preparation
6. Standards for Rehabilitation Products and Procedures
    a. Overview of Product Standards
    b. Standards for Adaptive Devices in Modified Vans
    c. Standards for Wheelchairs
7. Recommended Federal Government's Role in Development of Standards
8. Conclusion

INTRODUCTION

RESNA, the Association for the Advancement of Rehabilitation Technology, is pleased to provide the Subcommittee on the Handicapped with testimony concerning assistive technology for people with disabilities.

THE ASSOCIATION FOR THE ADVANCEMENT OF REHABILITATION TECHNOLOGY

Our association is a national, multidisciplinary association of rehabilitation professionals, engineers, technologists and consumers whose common interests lie in the development and the delivery of assistive technology which will meet the needs of citizens with functional limitations. RESNA brings together individuals whose credentials, activities, and interests vary widely, but all of whom are committed to designing, developing and evaluating technology, and to making the service delivery process work.

THE NEED FOR EFFECTIVE TECHNOLOGY DELIVERY SYSTEMS

RESNA commends this committee's efforts to include specific provisions for assistive technology services in the Rehabilitation Act and the Older Americans Act, and the committee's work in enhancing financial resources for technology utilization. We applaud your interest in developing legislation that would enhance the ability of the states to develop effective programs for delivering assistive technology, both the devices and the related support services systems. As we stated in testimony (attached) last week before the Subcommittee on Select Education of the House Committee on Education and Labor: "Advancing technology is providing enhanced opportunities for increasing independence and life fulfillment for people with disabilities.....The major barriers that prevent access to these new technologies for the vast majority are due to the total absence of, or fragmentation of, the delivery system and its associated payment structure."

THE URGENT NEED FOR QUALITY ASSURANCE MECHANISMS

Our colleagues will be presenting considerable testimony during the hearings before you on May 19 and 20, about the benefits of appropriately applied technological support and about the problems in the delivery and payment systems. RESNA's attached House testimony also addresses these issues. In its statement today, RESNA would like to target its testimony on the issue we consider to be of singular critical importance: Quality Assurance.

In rehabilitation technology service delivery, quality assurance involves two basic areas:

(1) the quality of service rendered -- measured in terms of personnel (certification) and facilities (program standards/accreditation);

(2) the quality of the equipment -- measured in terms of device safety and performance (standards).

Why is quality assurance so urgently needed? Because consumers have a right to a baseline quality in the level of services and devices they use. However, although this reason is very important, it may not strike you as "urgent". The urgency appears at the most basic economic level. Repeatedly you will hear in testimony of the importance of increasing the availability of funding for assistive technology. Quality assurance mechanisms are urgently needed because they are intrinsically tied to third party reimbursement. This trend is increasing rapidly. Efforts to secure adequate reimbursement of rehabilitation technology and related services will be blocked unless we have some acceptable form of certification in place.

In 1986, the Electronic Industries Foundation convened a National Task Force on Third Party Payment for Rehabilitation Equipment. The task force cited a variety of problems with third party payment for rehabilitation equipment which, upon reflection, point to this critical need for quality assurance. Five problems in particular warrant reemphasis.

1) There is serious unfamiliarity with available rehabilitation equipment and related services among clinical and payment decisionmakers. This unfamiliarity in many cases translates into either underutilization or inappropriate application of existing technology. Conversely, the more familiar decisionmakers are about equipment and related services, the more capable and confident they become in judging the relative value of each in any given case.

2) There is a significant lack of reliable, objective information that provides quality assurance and supports decision-making. The task force discussed in detail the need for cost-benefit and cost-effectiveness information that attests to the quality and appropriateness of equipment and services in given situations. Such information would support clinical and payment decisionmaking. The lack of such information exacerbates quality assurance concerns among decisionmakers, particularly when their inherent familiarity with equipment and services is relatively limited.

3) Payment decisionmaking criteria are not well defined at policy levels, making it more difficult for clinical and claims representatives at the case level to judge with confidence the appropriateness of given alternatives. Policies that require decisions be made consistent with rather vague outcomes, such as "medical necessity," create interpretive problems at the claims level. Justifying decisions solely upon the grounds of medical necessity, for instance, provides inadequate parameters within which clinicians and claims representatives must gauge quality or appropriateness of a particular decision. There is no objective way to judge how medically necessary a given intervention is, nor what outcomes result. Selection decisions, therefore, are made and ratified with few assurances for the payer other than an assumption that the initial decisionmaker is someone with sufficient qualifications and individual integrity.

4) A "vendor-driven" system predominates, where clinicians defer to the expertise of equipment vendors in cases where need

for technology is indicated. Insofar as an equipment vendor considers the comprehensive needs of a customer/client, while conducting the business of delivering equipment, a quality decision can be presumed. A vendor-driven system encounters problems, however, when vendors are asked to perform conflicting roles. Quality assurance within such a system is dependent, again, upon the integrity of the technical expert making the decision.

5) Finally, given the aforementioned quality assurance concerns, too often payment policymakers attempt to address those concerns through coverage restrictions. The value of a particular type of equipment or service does not need to be considered when it is unilaterally denied coverage. This method for dealing with the need for quality assurance is suspect. It does not allow decisionmaking flexibility, flexibility that is usually critical for appropriate application of rehabilitation technology. Recognizing that quality assurance is a critical problem for third party payers, presumably there are better ways to address that problem, other than relying upon rather rigid coverage controls.

THE NEED FOR A NATIONAL STUDY ON CERTIFICATION

Medicaid in at least two states is examining ways to provide reimbursement for rehabilitation engineering/technology services. These agencies want to know how to recognize a qualified practitioner. They can understand how to recognize a supplier of products. There will need to be a set of criteria developed for providers of services.

The 1986 Rehabilitation Act Amendments included rehabilitation engineering services. As defined in the '86 Amendments, "the term rehabilitation engineering means the systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of and address the barriers confronted by individuals with handicaps in areas which include education, rehabilitation, employment, transportation, independent living, and recreation." Who is qualified to provide (and get paid for providing) "rehabilitation engineering services"? The only clarification in the law is: "personnel skilled in rehabilitation engineering technology". Each state is interpreting this differently. Some will only reimburse someone with a master's degree in engineering or a Professional Engineer license;, others are looking for other forms of existing credentials; some are not limiting the skilled personnel to credentialed professionals.

Better quality assurance mechanisms must be established in order to increase the decisionmaking confidence of both third party funding sources and consumers themselves. Without some form of standards and certification, appropriate levels of payment, especially from the medically oriented funding sources will never be attained. The present situation is a Catch 22 - no funding for services without standards, no standards without service delivery track record on which to base standards. RESNA considers this to be the single most critical issue, one which requires immediate attention.

Clearer role and function definitions of the personnel who are involved in service delivery and direct implementation of rehabilitation technology are required. Key qualifications and basic competency areas need to be identified and used as a basis for developing certification guidelines for rehabilitation technology personnel. This quality assurance concern should be approached from a national perspective. Guidance and technical assistance must be available to the states as they implement quality assurance procedures. Without some uniformity, new barriers to assistive technology service delivery will be imposed. We do not currently have materials developed to provide any kind of unified approach to technical assistance on issues such as development of state standards and certification procedures.

RESNA recommends that legislative mandate be given for an indepth study of the development of standards and certification procedures related to assistive technology service delivery. It should be geared to providing national uniform basis for quality assurance, that would include standards and certification procedures, and closely related areas like personnel preparation. We recommend that the study include a demonstration component, wherein two or three states could serve as demonstration/test sites to help plan the study, and to evaluate and fine tune study results so a workable system could be ensured for state implementation.

THE NEED FOR TRAINING/PERSONNEL PREPARATION

There are also critical issues of personnel preparation, both preservice and post service training. Manpower development requires that individuals be trained to purchase as well as to provide assistive technology. A priority ranking of critical needs by state vocational rehabilitation agencies placed training as the most important issue faced in the use and application of rehabilitation technology (Institute on Rehabilitation Issues, 1986). Estimates on the amount of training staff have received to prepare them to directly provide or to make arrangements to purchase rehabilitation technology services are very low. This scenario is repeated throughout our public school systems, rehabilitation facilities, aging and health care programs.

Qualified technology specialists to work within a coordinated delivery system are urgently needed. Existing training institutions will respond to these training requirements if the financial incentives are made available through the existing granting process.

RESNA recommends that training for technology specialists be given high priority. The capabilities of rehabilitation technology that exist today and the promise of future developments for persons with disabilities depend on the availability of qualified personnel. We currently have extensive technological resources which are not being effectively provided to many of the millions of Americans needing assistance. Efforts to enhance the use and application of rehabilitation technology must include provisions for meeting these critical training needs.

STANDARDS FOR REHABILITATION PRODUCTS AND PROCEDURES

Quality assurance must of course provide for more than personnel preparation and certification. The technology must also be considered.

Voluntary product standards can have important benefits for both consumers and producers. The first voluntary standards for products used by people with disabilities are just now being completed. RESNA applauds the Federal Government's financial assistance for, and participation in, the development of these standards and guidelines. Continued Federal support of this type is needed to complete the development of these standards and to implement them. Additional Federal support also is needed to develop product standards for other assistive devices. This Federal support, in the form of both expert participation and financial assistance, should support private sector consensus standards activities.

Overview of Product Standards

"Product standards" are model specifications prescribing requirements for a product, material, or procedure. They often include test procedures for determining whether specified requirements are satisfied. Product standards can be referenced, in part or in whole, within individual procurement specifications.

It is important to distinguish between design requirements and performance requirements in product standards. Design requirements are expressed in terms of simple physical attributes such as dimensions, shape, and specific material; they are used to assure interchangeability or compatibility between system components. Performance requirements, on the other hand, are expressed in terms of functional attributes such as product durability and energy efficiency. Unfortunately, performance attributes usually are more difficult to measure than design attributes, and often are more difficult to convey in understandable terms to consumers.

Consider the common electric light bulb. Design attributes include the shape and dimensions of the bulb's base. Performance attributes include the bulb's brightness, energy consumption, and average lifetime. Design requirements for the base's shape and dimensions allow interchangeability of 60 watt and 75 watt bulbs, as well as compatibility of these bulbs with all ordinary lamp sockets. However, design requirements in standards can impede the introduction of product innovations, and can lead to restraint of trade. To avoid "locking in" any one product design, all requirements not relating to interchangeability or compatibility of system components should be specified in standards as performance rather than design requirements.

Standards for Adaptive Devices in Modified Vans

Moving more closely to rehabilitation technology, consider product standards for adaptive devices in vans modified for people who utilize wheelchairs. These Adaptive Devices Standards are being developed by a Society of Automotive Engineers (SAE) committee. They contain an appropriate mix of performance and design requirements, with corresponding test procedures, for (a) manual and (b) power-assisted automotive adaptive driver controls, (c) wheelchair lifts for vans, (d) wheelchair and occupant restraint systems, and (e) structural modifications to vehicles. A computer program also has been developed which predicts whether a particular wheelchair will fit in the trunk or behind the seat of a particular automobile.

The SAE Adaptive Devices Standards will be "consensus standards" since manufacturers, vendors, users, government regulators, researchers, and other interested parties all are participating in the SAE Committee using procedural rules that ensure all points of view are carefully considered. The SAE Standards also will be "voluntary standards" since SAE has no regulatory authority. However, when promulgated, regulatory authorities such as State agencies can reference the SAE Standards, utilizing all or part of the voluntary standards in their codes.

Safety is one of the important features addressed in the SAE Adaptive Devices Standards. Adaptive devices complying with these standards are expected to be safer devices, and to have other quality attributes which meet or exceed the specified requirements. Some foresee reduced liability risks for manufacturers and vendors whose products comply with these standards. Manufacturers and vendors of adaptive devices are having serious problems with liability insurance. High insurance costs have forced several manufacturers of good quality products to go out of business.

Standards for Wheelchairs

The RESNA/ANSI Wheelchair Standards are intended primarily to be information disclosure standards. Information disclosure standards are a relatively new type of product standards. They are the basis for providing "comparative product performance information", i.e., performance information obtained in accordance with standard tests, and presented in a standardized format. Standard tests are essential for comparing "apples to apples" across brand names. Standardized format of displayed test data allows easier comparisons of alternative products. Performance tests are essential if performance information is to be presented.

Performance information is much more useful than design information for product comparisons by consumers. Consider again the light bulbs. Performance information such as bulb brightness, energy consumption, and average lifetime is more helpful to consumers comparing bulbs than design information such as the filament diameter, length, and material. The same is true for more complicated products such as wheelchairs. The RESNA/ANSI Wheelchair Standards specify tests for measuring performance attributes such as durability, maneuverability, static and dynamic stability, obstacle climbing ability, and energy consumption.

Generally, information disclosure standards do not contain pass/fail criteria. They are particularly suitable when there are no sharp thresholds between acceptable/unacceptable levels of performance. Some wheelchair users, for example, may be willing to sacrifice durability to get more maneuverability, or vice versa. Appropriate trade-offs depend on an individual's needs and preferences. There is no "best" combination for everybody, so pass/fail criteria are not appropriate in information disclosure standards. Fortunately, standards having no pass/fail criteria have almost no risk of unfairly excluding new products from the market. The possibility of unfair restraint of trade has been a serious concern for standard developers.

When comparative product performance information becomes available, impressive benefits can result for both consumers and manufacturers/vendors. Consider the potential consumer benefits first. Wheelchair users, prescribers, and third party payers will be able to make more informed procurement decisions, making it more likely that rehabilitation devices serve the needs of users. Comparative product performance information can be utilized to counter the "low bid syndrome" by helping to justify a legitimate need for a device having better than minimum product performance.

From the manufacturers' and vendors' perspectives, those who offer the best performing products at reasonable prices will be more likely to be rewarded in a market having comparative product performance information. This will lead to improved marketplace competition, and will encourage the introduction of improved products at competitive prices. Comparative product performance information will assist manufacturers and vendors wanting to supply quality products to compete against inferior products, since the trade-off between quality and costs will be clearer. The dissemination of such performance information by a well known independent organization will be a valuable supplement to regular advertising by participating manufacturers/vendors.

Recent news media publicity about airline service illustrates the potential benefits from the dissemination of performance information. With the disclosure of "on-time arrival" records, supposedly generated using the same counting procedures, the airlines have become increasingly concerned about their performance. While it is true that this example concerns performance of a service rather than a product, it is reasonable to hope for similar benefits from dissemination of product performance information.

The RESNA/ANSI Wheelchair Standards for powered and manual wheelchairs will be the first information disclosure standards for assistive devices. Most sections of the Wheelchair Standards are in the final stages of review. Plans are now being made for their implementation. Their implementation will involve three additional steps, all of which will require considerable effort: (1) Someone (perhaps participating manufacturers or vendors) must test wheelchairs in accordance with the test procedures in the standard. (2) The resulting test data must be collected and put in a format allowing reasonably easy product comparisons. At that point, the information becomes comparative product performance information. (3) This information must be disseminated to those who will benefit from its use. Of course, safeguards must be in place to ensure that the disseminated information is accurate.

RECOMMENDED FEDERAL GOVERNMENT'S ROLE IN DEVELOPMENT OF STANDARDS

The development of product standards is an arduous, expensive, time consuming task. However, the promise of benefits evidently justifies the effort for the numerous contributing individuals and organizations. Financial, administrative, and technical support are being given by industry, by wheelchair and modified van users, by researchers from the R&D community, and by State and Federal agencies.

Federal support has been particularly important. Funds from the National Institute on Disability and Rehabilitation Research (NIDRR) and from the Veterans Administration (VA) are helping to expedite the development of the SAE Adaptive Devices Standards and the RESNA/ANSI Wheelchair Standards. Additional contributions of staff time and travel, as well as laboratory tests have come from these and other Federal agencies such as the Food and Drug Administration and the National Institutes of Health.

Note that this Federal support involves funding for, and participation in, private sector consensus standards activities, along with similar support from the private sector. Such support serves national needs by strengthening the nation's voluntary consensus standards activities. Both Government agencies and private sector organizations benefit from standards developed cooperatively by Federal, State, and private sector experts.

International standards, which are developed in the U.S. through private sector consensus standards organizations, can enhance international commerce. SAE and RESNA are accredited organizations in the American National Standards Institute (ANSI). Members of the RESNA/ANSI Wheelchair Standards Committee are active participants in the International Standards Organization (ISO) Technical Committee on Wheelchair Standards (TC-173), often serving in leadership roles. As a result, the RESNA/ANSI Wheelchair Standards will be almost identical to the ISO Wheelchair Standards.

Federal support for, and participation in, private sector standards activities has been Government policy since the LaQue Advisory Panel Report which was published about 1970, and OMB Circular No. A-119 issued in 1982. As an example, the Veterans Administration reportedly is planning to replace their old wheelchair standards in VA procurement specifications with the new RESNA/ANSI Wheelchair Standards.

Regarding product standards, RESNA recommends that:

1. Congress should encourage continued Federal support for the completion and implementation of standards and guidelines for Automotive Adaptive Devices, Wheelchair Standards, and Computer Accessibility.

2. Congress should authorize Federal support for the development and implementation of additional product standards needed for other assistive devices.

3.Government support and participation in the development of product standards should be through private sector consensus standards organizations. Primary responsibility for developing product standards should be left to societies and trade associations which are concerned with developing voluntary consensus standards. The Nation's needs are best served when Federal support is as a participant, albeit an important participant, in national consensus standards activities.

CONCLUSION

There are existing and burgeoning technology applications to meet needs of people with physical, sensory, and cognitive disabilities. Appropriate technology services reach far beyond the stereotype of wheelchairs for individuals with mobility impairments; but yet are not readily categorized into programmatic areas such as Head Injury, Spinal Cord Injury, Geriatrics, Pediatrics, etc. However, regardless of how the people and the technologies are pigeonholed, we must ensure that we avoid an overly restrictive view of who might benefit from the creative application of appropriate technology. Technology impacts all of our lives. Adapted toys, assistive learning devices, restructured jobsites for older workers, "cognitive orthoses" -- more people than one might imagine will at some point need assistance in pursuing the basic elements of life's quality, independent living, education/vocation and recreation. Development of the capacity for an integrated technology service delivery system must move beyond outmoded and limited views of who can benefit from technology. It must also move beyond limiting notions of which types of technology can provide benefit.

The rapid onset of need and the limited time for growth of rehabilitation technology services has provided little historical perspective on the optimum model for this process. There are many local, and regional issues that will dictate the method of initiating a service system, and it is imperative that further analysis of these conditions be conducted to determine the common elements that produce high quality, effective results. We must strive for consistency and integrated systems which are based on some similar assumptions.

Quality assurance strategies must be incorporated into the development of a nationwide rehabilitation technology delivery system capacity. These strategies must be built not only into the obvious areas (personnel training and product development), but also into the information networks, the data collection approaches and the capacity building efforts we are about to embark on.

The membership of RESNA stands ready to provide further informational support to this Committee in its efforts to develop assistive technology legislation that will enable disabled Americans of all ages to participate in the mainstream of our increasingly technological society.

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STATEMENT

PRESENTED BEFORE THE

SUBCOMMITTEE ON SELECT EDUCATION

OF THE HOUSE COMMITTEE ON

EDUCATION AND LABOR

MAY 10, 1988

ON

TECHNOLOGY AND DISABILITY

ON BEHALF OF

RESNA,

Association for the Advancement
of Rehabilitation Technology

Witness: Alexandra Enders

1. Introduction
2. Association for the Advancement of Rehabilitation Technology
3. Background: The Need for a Service Delivery System
4. The Development of the Field of Rehabilitation Technology
5. Current State of the Art in Assistive Technology Service Delivery Systems
6. The Payment System
7. Manpower Development/Quality Assurance
8. Resource Allocation Issues
9. Conclusion
10. List of Recommendations

Attachment 1. "Hanging Onto The Coattails of Science", Alice Loomer. Rehabilitation Gazette. 1982

Attachment 2. Chart: The Current Development of Technology Service Delivery Systems.

Introduction

Mr. Chairman, it is a privilege to present testimony on the development of the field of rehabilitation technology. My name is Alexandra Enders. I am a occupational therapist, and the project manager at the Electronic Industries Foundation for an NIDRR sponsored R&D grant investigating the development of an integrated network of assistive technology service providers across the country. I am also the editor of the Rehabilitation Technology Sourcebook. My involvement with assistive technology started in the community at the Center for Independent Living in Berkeley, California, and has expanded from direct service provision to include research, evaluation and training. I am testifying today on behalf of RESNA, the Association for the Advancement of Rehabilitation Technology. I am a founding member of RESNA, and currently on the Board of Directors and a member of the Executive Committee.

Association for the Advancement of Rehabilitation Technology

RESNA is concerned with transferring science, engineering, and technology to the needs of persons with disabilities. Our Association and the nearly 1000 individuals it represents welcomes the opportunity to comment on issues related to assistive technology for individuals with functional limitations. Our members are rehabilitation professionals from all pertinent disciplines, manufacturers, providers and consumers. Our goal is to promote and support the research, development, dissemination, integration, and utilization of knowledge in rehabilitation technology and to assure that these efforts result in the highest quality of service delivery and care for all disabled citizens.

Background: The Need for a Service Delivery System

Advancing technology is providing enhanced opportunities for increasing independence and life fulfillment for people with disabilities. In order to capitalize on the promise of these existing and emerging technologies, a systematic delivery system must be available which can provide the average disabled person the ability to:

- comprehensively identify personal needs for technology,
- review the technology that exists in the field,
- purchase equipment so that costs do not produce an inequitable hardship.

Rehabilitation technology includes not only the devices but also the systems which people use to obtain technological support. Until very recently, the emphasis has been primarily on the equipment, and strongly influenced by research and development (R&D) activities. The orientation has been "market push". As the equipment was developed, attempts were made to push it into the marketplace. Not enough emphasis was placed on the delivery process; in large part due to the lack of funding. Additionally, little recognition was given to the ongoing nature of a disabled person's need for technological support. (One may only need to learn to drive once; but if one needs an adapted vehicle, one will probably continue to need adapted vehicles. If one requires a motorized wheelchair, or a communication device, it is not likely that need will be outgrown.) Assistive technology services frequently do not fit well into our traditional service delivery systems geared to cure, closure, aging out, graduation, or some other fixed endpoint. Significant problems, particularly related to funding, occur for example when transitioning between systems, or when the need for ongoing maintenance and replacement of the equipment occurs. Equipment was, and still is, often viewed as a one shot event, an attitude that is reflected in the policies of many of the sources for funding assistive technology.

Though not often recognized, one of the more important factors for the increased attention given rehabilitation technology in the U.S. is the consumer based Independent Living movement, with Federal legislation supporting equal opportunity for disabled persons and equal education for disabled children. Technological advances helped motivate the Independent Living movement by promising more options, and the more active community-based disabled consumer is now creating:
o a more widely recognized market for equipment,
o societal impetus for change,
o ideas for technological innovation.
However, there has only been a single generation of severely disabled persons who have benefitted from significant technological intervention. We are only now beginning to get a sense of the longer term issues that a comprehensive support system must address -- such as: Where does the next adapted vehicle come from? How do you upgrade computer adaptations to remain competitive in the workforce as more sophisticated technology becomes available? What is a rehabilitation agency's role when former clients find they need financing for subsequent generations of equipment? Should a disabled child be entitled to take her school system purchased communication device home over the weekend?

The Development of the Field of Rehabilitation Technology

People have been using devices to compensate for impairment since before written history. The modern history of assistive technology begins in the 1940's with the post World War II R&D effort in the field of prosthetics. In the United States, much of the framework for national research developed during the 1940s. The structure and philosophy of governmental support of science and technology in the USA can be traced to the 1945 report of Vannevar Bush, called Science: The Endless Frontier (Report to the President on a Program for Postwar Scientific Research, 1945). This report has heavily influenced all of the country's research and development activities, including rehabilitation technology. The research agenda for the field of rehabilitation technology grew out of the agenda of its precursor, the limb prosthetics research program, which can be traced to a January, 1945 meeting in Chicago of medical, scientific, engineering, and administrative personnel of the Allied forces. This meeting was concerned with the care of war amputees and with the improvement of limb prosthesis technology. Federal support of prosthetics research grew out of that meeting as did the Committee on Prosthetics Research and Development (CPRD) of the National Academy of Sciences/National Research Council (NAS/NRC). CPRD effectively guided the research programs in prosthetics and other areas of rehabilitation technology for nearly thirty years through advice to government funding agencies, through coordination of research efforts (workshops, evaluations, panel studies, etc.), and through information dissemination. The original agenda for rehabilitation engineering/technology research in this country came from this committee (see, Rehabilitation Engineering: A Plan for Continued Progress, NAS, April, 1971). In 1972, a formal program of research and development for rehabilitation technology that included the establishment of Rehabilitation Engineering Centers was initiated, chiefly by the Rehabilitation Services Administration and the Veteran's Administration. Research of this nature (wider than just prosthetics) existed previously on a small scale, mostly funded on a piecemeal basis through field-initiated grant proposals.

The prosthetics research program, begun in 1945, had a revolutionary influence on the limb prosthetics field, and by 1955 this research program was having a major influence on limb fitting techniques and limb prosthesis technology. This positive influence has continued, albeit with less dramatic effect than in the early years when science and technology were so new to the field. However, new and dramatic advances appear on the horizon because computer-aided design and computer-aided manufacturing (CAD/CAM) may revolutionize the field again during the next decade.

The influence of funding research connected with the wider field of rehabilitation engineering has been no less dramatic than it was earlier in prosthetics. The provision of technology had become part of the emerging rehabilitation process in this country. The medical rehabilitation system in the 1950's and 1960's documents creative attempts to apply adapted equipment, though the technology itself was quite limited. In 1972, some technology existed for disabled people--not a lot, and much that existed was of poor quality--but almost no technical equipment existed for persons with severe disabilities, the very persons who needed it the most.

Since the early 1970s, when research funding was significantly expanded for rehabilitation engineering, the quantity and the quality of available equipment has markedly improved. ABLEDATA, a database of commercially available rehabilitation equipment, now lists over 15,000 products from over 1800 manufacturers. No one would claim that this change was all brought about by the research funding but it cannot be denied that this funding had a powerful direct influence through the actual research projects and possibly an even greater influence indirectly. When examining future R&D appropriation levels, it is vital that the benefits reaped from the by-products of R&D activity be factored in. Foremost are the development of people resources and expertise. Many individuals who started out in R&D have become the pioneer clinicians in the field, and the entrepreneurs in industry. R&D provided the development of a heightened awareness of the field, and the basis for interchange of ideas, publications, meetings, professional education, as well as the basis for service and equipment standards.

There have been exemplary, pioneering efforts in rehabilitation technology service delivery accompanying the R&D efforts. However, the field of rehabilitation technology service delivery has recently gained momentum, and more clearly emerged in the past few years. RESNA which was started 10 years ago primarily by leaders in the field of R&D, has dramatically expanded its emphasis on service delivery in the last 4 years. A RESNA survey done in 1987 lists over 400 programs which identify themselves as providers of rehabilitation technology services, and we know there are many more programs not yet included.

Today, the emphasis is changing from "market push" to "market pull"; more attention is being addressed to the dynamics of delivery systems, and to issues related to funding and financing for assistive technology. A survey done 2 years ago by the Electronic Industries Foundation Rehabilitation Engineering Center clearly indicated that manufacturers are able to provide the assistive technology when a financially based market demand exists. They do not need R&D products transferred to them, as much as they need to be paid for the products they develop. This changing emphasis is also reflected in the evolving nature of the Rehabilitation Engineering Center Program of the National Institute on Disability and Rehabilitation Research. We are seeing more research priority given to delivery system issues such as Equipment Evaluation and Quantitative Assessment, thereby developing a scientific basis for matching an individual with the technological support required.

There is another account, from the consumers perspective, that must accompany this brief history. Given the lack of a coordinated service delivery system for assistive technology, it is important to understand how disabled individuals have actually been getting technology that fits them. However, that account is better told by a consumer. Alice Loomer's article "Hanging Onto The Coattails of Science" (Rehabilitation Gazette, 1982) has been attached (Attachment 1.) so you can read her brief but poignant description of the difficulties consumers have had in getting their assistive technology needs met, as well as her suggestions for improving the situation. As you consider actions that would assist disabled people of all ages to benefit from technological assistance, it is vital to remember individuals like Dr. Loomer, for she is just one of the majority of disabled persons who are in no formalized ongoing intervention system, and may have no need to be, yet she has an ongoing need for assistive technology.

Current State of the Art in Assistive Technology Delivery Systems

The development and provision of technology has long been accepted as an integral part of the rehabilitation process in this country. Artificial limbs and braces, wheelchairs, crutches, etc. have been available to people with physical disabilities for many years. More recently, advances in engineering developments are resulting in more sophisticated assistive devices for disabled people with physical or mental impairments - both congenital and acquired. Individuals with loss of: sitting stability, mobility, verbal expression, hearing and vision, hand function, cognitive awareness, etc. can now substantially benefit from new and emerging assistive device technology. Comparative studies and direct observation have shown time and again the value of assistive devices in providing improved function, increased independence, access to educational/vocational pursuits; and most importantly, a life of economic and personal fulfillment. The major barriers that prevent access to these new technologies for the vast majority are due to the total absence of, or fragmentation of, the delivery system and its associated payment structure.

There are several different frameworks that could be used to describe the current state of the art in delivery systems for technology for individuals with disabilities. These include categorizations such as: level of need/level of support; society's perception of need: the health/medical/sickness orientation vs the public health/nonmedical/-wellness model. However, the most realistic way to describe how disabled people get their equipment is to admit there really is no system, and that uncoordinated third party reimbursement systems drive both the distribution and the development processes. Since public policy related to reimbursement is most often categorically tied to age, a chart is included (Attachment 2.) depicting the current development of technology service delivery systems for disabled people of all ages and varying levels of service intervention needed. This chart shows the gaps in the delivery system. It is interesting to note that even though there are disabled people of all ages in each of these categories, service delivery systems seem to target one age group per category.

Systems are not developing within any age group that would provide a continuum of service intensities to match the continuum of needs. This matter deserves further analysis. It may be one reason why there are so many unmet needs, despite the fact that there are a considerable number of programs related to technology provision. It could also be one of the prime reasons there is such difficulty transitioning between systems -- we may all be talking about disabled people, but we are not discussing the same types of disabled people, or the same types of intervention needs. Is there any question that frustration would exist when policy makers from, for example, special education and vocational rehabilitation try to agree on a common agenda related to assistive technology for individuals with functional limitations? It may be time to acknowledge that we are all seeing the proverbial "elephant" from totally different perspectives, to take off our "blindfolds" and see what we have our hands on. It is also time to include the "elephant" in the dialogue.

This chart also explains why manufacturers have such a difficult time marketing products to certain categories of people. We know that for certain types of products, the demographics indicate a market should exist. However, with only three of the nine combinations currently available, six potential market channels are still undeveloped, and the disabled individuals who could benefit from this technology remain unreachable.

The older population must be included in all discussions related to assistive technology. Policy and resource allocation for assistive technology for older, functionally limited Americans and for younger disabled Americans is clearly connected, and whichever group precipitates a change, both groups will benefit (or suffer). We no longer have the luxury of pretending that these systems do not at least indirectly influence each other. Other countries have dealt with these issues in a more comprehensive and comprehensible manner. It is time for us to gain a better understanding of real needs, and to devise systems that will provide appropriate community based support for disabled people of all ages, and with a wide spectrum of needs.

The legislation authorizing the involved agencies and their programs has evolved over time; with varying degrees of concern regarding federal/state coordination and cross agency networking. As a result, we now have a technology delivery system that is plagued with gaps in services; confusing in coverage policies, lacking in continuity throughout the life cycle, with accessibility dependent on disability type, age, or vocational potential or health status. The operational structure is now a mosaic of state and federal bureaucracies that makes equal access and acquisition of timely services extremely difficult for any individual disabled person.

The Payment System

A functional delivery system must be supported with responsive payment mechanisms. The complex mosaic of payment programs must be coordinated and simplified. Disabled individuals of all ages should have access to financial support as may be appropriate and necessary in order to provide a lifelong continuum of "reasonable" technology services so that the costs do not produce an inequitable hardship for the disabled individual.

It is becoming increasingly evident that to derive the potential benefits of assistive device technology for both the individual and society at large, increased financial investments by both the public and private sectors is required. Medicare is the "flagship" of the third party payment system. It charts the course that other agencies, as well as private insurance companies, look to for establishing guidelines on coverage policies and reimbursement procedures. The present Medicare policy related to assistive device technology is defined under Part B as Durable Medical Equipment (DME). In part, the policy states that Medicare is prohibited from paying for items and services "which are not reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member". This policy, designed for a more primitive era of assistive technology, is no longer adequate as disabled people seek to benefit from the potential of: powered mobility, assistive listening devices, speaking machines for the non-verbal, enlarged print for the visually impaired; as well as obtain increased access to more traditional assistive devices, such as, toileting and dressing aids, improved wheelchairs, feeding aids, and specialized seating devices -- all designed to increase the independence and self-fulfillment of persons with chronic disabilities.

The technological support needs of an individual with a functional limitation should be met with the least stigmatizing, most reasonable equipment available. In some, perhaps many, cases the most suitable and effective technological solution is available as a mass market product. Current third party reimbursement policies frequently prohibit payment for off the shelf consumer products, even when these can be shown to be [1] equally or more effective, [2] less expensive than a strictly disability oriented product, [3] less stigmatizing for the disabled person to use.

The current delivery system for assistive technology is based in or heavily influenced by the medical model and its focus on sickness. To prevent abuse in the medical system, policy has tried to ensure that services and equipment would not be desirable to non-sick people. The people who need assistive technology often do not fit into this model well. Most are not sick, yet they need compensatory technology to achieve equity with non disabled peers.

Until there is a broader societal shift in how disability is perceived and compensated, public policy can at least remove the barriers to securing needed and currently available technology.

One economic barrier that should be reevaluated is the present insistence that mass market consumer products are outside the inventory of reimbursable assistive technologies. Even in service systems that are allowed by existing policies to purchase regular market products, there is a genuine reluctance to do so.

Medicare payment policies are primarily designed to support the medical needs of beneficiaries with acute health care needs, who may need a product for a limited period of time. The dominant philosophy is to purchase or rent low cost equipment. This may be appropriate for a segment of the disabled population, but is totally inadequate for those with permanent lifelong disabilities, whose needs may transcend traditional definitions of medical necessity. It is this latter population that has the greatest potential of deriving the most benefit from assistive device technologies.

Furthermore, individuals with long-term disabilities may have need for multidisciplinary services that can be tailored to meet the unique technical needs of the individual. These needs usually include: information services, comprehensive evaluation, technology provision, follow-up training and a reliable source of maintenance and repair. Too often payment programs do not understand the necessity of related services and/or expect the cost of the services to be included in the price of the device. Yet the reimbursement level is set to cover only the cost of the equipment itself.

As a result of the present special interest legislation, and varying financial curtailment programs at both federal and state levels, we now have a complex patchwork of public and private financial support that is rapidly polarizing towards the largely outdated Medicare DME model (Part B). This fragmented financial support system does not foster the development of coordinated services that can systematically provide access to appropriate assistive technology that should be consistent with an advanced technological society.

A major concern at this time is whether federal legislation, combined with federal/state/private sector partnerships, can be evolved that will ameliorate this critical social and administrative deficiency in our delivery system and its financial support structure. Many options exist for the development of effective models for the provision of rehabilitation technology services. There is no single model, however, that will meet the needs of all individuals with disabilities or those of a particular agency. Comprehensive planning between agencies is needed to identify which service delivery options may work best for a given state or region. Multi-agency government and private sector participation is essential, especially at the statewide delivery level. We recommended that legislative initiatives be developed and enacted that will foster these partnerships in the future, and that Congress provide the authority for coordination, systems planning, and systems implementation.

Manpower Development/Quality Assurance

Training of personnel to deliver rehabilitation technology services must be approached on at least a two-fold perspective. Clearly, the need for undergraduate level or advanced training of service delivery personnel in the application of rehabilitation technology is apparent. This represents only a partial answer, however, to the manpower needs and, at best, is a long term solution since the capability to graduate specialized, trained professionals is still very limited. On an immediate short-term basis, the need to train existing staff must be provided. A comprehensive series of in-services and extended workshops must be available to the wide spectrum of personnel who are involved directly in the provision of services to individuals with severe disabilities either as direct service providers or purchasers of these services. The term "purchasers" refers both to professional staff such as vocational rehabilitation counselors, special educators, administrators and others who are involved in recommending or utilizing rehabilitation technology services, and also directly to disabled consumers themselves.

Meeting the training demands for service delivery personnel for rehabilitation technology is a complex and challenging task. Planning to meet these needs should include active involvement by consumer groups and professional associations. The following are major issues that should be considered:

1. Provision of a coordinated program of state and regional training activities to develop a general awareness of rehabilitation technology for existing rehabilitation, health and human service, education and private sector staff.

2. Support for the expansion of existing long-term training programs and the development of additional programs to insure a supply of trained, well-qualified personnel.

3. Implement a regional network of advanced training activities designed to upgrade the skills and capabilities of rehabilitation technology service providers.

Resource Allocation Issues

Technology must be viewed in context. Resource allocation decisions are influencing the individual's ability to select the best combination of options for community-based living. A piece of hardware is not the only way to solve a problem. It is one option. Others include: personal help, learning new skills, adapting the environments, redefining the problem. It would be unlikely that anyone but a "techie" would approach an everyday living problem by asking "What gadget can I get to solve my problem?" Most of us look at the range of possible options, determine the tradeoffs, the resources available, then make a decision. However, where technology is concerned, we already are learning to write reimbursement documentation for assistive technology in terms of cost reduction/effectiveness (e.g., if this widget is provided, it will reduce the need for attendant care services). It will indeed be unfortunate if supportive services which should be considered in combination (personal assistance + technological assistance + environmental adaptation + training/retraining = community-based support system) are seen as discrete alternatives to each other (personal assistance or technological assistance or environmental adaptation or training/retraining = ????). These issues can be seen most clearly around technology because it is so tangible, but it is clear that similar issues exist in all the supportive services connected to what the medical model might call "chronic care needs". We do not suggest simply providing more of anything; but to carefully look at how and what is being provided; and why it is being provided (or not being provided).

It is critical that players in all areas of this complex puzzle begin working together to avoid fragmentation and the inevitable turf battles that will result if these services are pitted against each other. Denial of services is clearly one way to reduce costs. We are already finding that many of the types and combinations of services and products needed by disabled persons are effectively excluded from reimbursement.

Conclusion

The independent living movement, a growing elderly population, technological opportunities, and younger generations who expect technological solutions to be readily available, are coming together to generate a fertile field for advancing the current state of the art in applied technology. There is urgent need for the capacity to plan and implement coordinated assistive technology delivery and payment systems that can surmount the barriers imposed by previous legislation and lead to the availability of quality technological assistance which truly meets the needs of each disabled person.

The membership of RESNA stands ready to provide further informational support to this Committee in its efforts to develop assistive technology legislation. As an association comprised of rehabilitation professionals, educators, manufacturers, suppliers, and consumers, we feel well qualified to participate in this landmark process.

LIST OF RECOMMENDATIONS:

1. Funding levels for rehabilitation engineering/technology research and development need to be increased. When examining future R&D appropriation levels it is vital that the benefits reaped from the by-products of R&D activity be factored in. Foremost are the development of people resources and expertise. Many individuals who started out in R&D have become the pioneer clinicians in the field, and the entrepreneurs in industry. R&D provides the development of a heightened awareness of the field, and the basis for interchange of ideas, publications, meetings, professional education, as well as for service and equipment standards.

2. There is urgent need for the capacity to plan and implement coordinated assistive technology delivery and payment systems that can surmount the barriers imposed by previous legislation and lead to the availability of quality technological assistance. A major concern at this time is whether federal legislation, combined with federal/state/private sector partnerships, can be evolved that will ameliorate the critical social and administrative deficiencies in our delivery system and its financial support structure. Comprehensive planning between agencies is needed to identify which service delivery options may work best for a given state or region. Multi-agency government and private sector participation is essential, especially at the statewide delivery level where many of the public funds are expended on technology. We recommend that legislative initiatives be developed and enacted that will foster these partnerships in the future, and that Congress provide the authority for coordination, systems planning, and systems implementation.

3. Systems are not developing within any age group that would provide a continuum of service intensities to match the continuum of needs. This matter requires further analysis.

4. The older population must be included in all discussions related to assistive technology. Policy and resource allocation for assistive technology for older, functionally limited Americans and for younger disabled Americans is clearly connected, and whichever group precipitates a change, both groups will benefit (or suffer).

5. Better quality assurance mechanisms must be established in order to increase the decisionmaking confidence of both third party funding sources and consumers themselves. Without some form of standards and certification, appropriate levels of payment, especially from the medically oriented funding sources will never be attained. RESNA considers this to be the single most critical issue, requiring immediate attention.

6. We recommend that training for technology specialists be given high priority. The capabilities of rehabilitation technology that exist today and the promise of future developments for persons with disabilities depend on the availability of qualified personnel. We currently have extensive technological resources which are not being effectively provided to many of the millions of Americans needing assistance. Efforts to enhance the use and application of rehabilitation technology must include provisions for meeting these critical training needs.

by Alice Loomer, Ph.D.

ATTACHMENT 1.

The gulf between science and the disabled is heartbreaking. Modern technology is capable of making the blind almost as if they could see, the deaf as if they could hear, and us as if we could walk. If they have the actuators and servomechanisms to walk a LEM on the moon, they also have the hardware to walk (and climb and sit) a quadriplegic on earth by automating braces and crutches, for example. But the gap between what is possible and what is likely will continue, for many reasons (some of which we can, perhaps, change).

We are brainwashed by the conventional. We often humbly accept what is as what must be. Starting one's thinking from scratch is very hard. It took me 60 years to realize I didn't have to put up with miserable tucked-in bedclothes. Now I sleep comfortably, my way, with a firmly anchored bottom sheet and a small light-weight throw that's easy to handle.

The disabled, by and large, have been given little knowledge of science and technology and have been so little encouraged in inventing, that they cannot design for themselves nor guide those who could. The same is often true of rehabilitation centers. Even in one's own town, there are craftsmen and experts ranging from telephone technicians to model plane clubs (experts in remote controls) whose help is lost because neither the disabled nor their rehabilitation centers see the possibilities.

Scientists and technologists have trouble picturing our real needs in practical (and cheap) terms, as they also do with those of the Third World. They are as brainwashed by the esoteric as we are by the conventional.

Manufacturers and distributors. Not only are we a very tiny market (how many bicycles and motorcycles to one wheelchair?) but for promotional and sales and service purposes, manufacturers need products so complicated that they have exclusive rights.

We, on the other hand, need equipment so simplified that it can be made from cheap, readily available parts and serviced by local repairmen, family, friends, neighbors (or oneself).

What's to do about it? Perhaps a lot more of what many readers are doing right now:

- Whenever we see a product that's clearly not user-oriented (like most reclining backs and adjustable foot boards); or equipment that could have used standard parts but didn't, we can protest to manufacturers.

We can keep reminding governments that simple design faults that bar us from independent living are costing the country millions of dollars annually. The conventional electric wheelchair is an engineering disgrace, as well as being thirty years behind the times. No appliance outlets. No provision for heated foot blankets and jackets, and not even a heated cover for one's driving hand. No user-operated back and leg rests. No power loading and unloading. No quick, easy handyman repairs.

Dr Loomer is a mixture of things: rehabilitation psychologist, 10 years, New York University, then psychotherapy practice in New York, writer, now partly retired consultant, Halifax, Canada, and since age 9, full-time schemer, improviser, inventor, and finagler to beat the rap of polio and lead her own life, her way.

- We can write to science, technology, and manufacturing journals and conventions asking them to be alert to any of their new developments that might have spin-offs in our direction. We ourselves can be alert to new discoveries, inventions, and products intended for other uses.
- We can learn to improvise, invent, supervise, or do more of our own construction. Like most people with polio, that most whimsical of diseases, I have an unreasonable pattern of weaknesses. If limited to commercial equipment, I would have been very helpless, so we (my family and I) were forced to develop all kinds of things: kitchens, hand controls, van lifts, even urinals. (There's nothing like a paper coffee cup, a small garbage bag, a bunch of Kleenex, and a rubber band!)

My first wheelchair was made by my teenage brother from a kitchen chair and his old bicycle — it worked fine until I outgrew it. My last is concocted out of an old E and J frame, a set of motor wheels installed by an apartment handyman, and wiring controls, figured out and put together by me. Its craftsmanship is deplorable, but it's the only wheelchair that could have kept me away from nursing homes and attendants. It stays on the road. (In twelve years, the longest it has ever been broken was 24 hours, once.) I made it. So I know how to fix it. It's easy to add conveniences.

I may have had to grit my teeth, I may have had to drive myself to learn about motors and wiring and relays. I may have failed almost as often as I succeeded, but I have equipment that fits *me.*

So I guess I'd better keep on saying, "There ought to be a way," and beating my brains out to find my own little bridges to science and technology.

Dr. Loomer is a mixture of things: rehabilitation psychologist, 10 years, New York University, then psychotherapy practice in New York, writer, now partly retired consultant, Halifax, Canada, and, since age 9, full-time schemer, improviser, inventor, and finagler to beat the rap of polio and lead her own life, her way.

Address: Alice Loomer, Ph.D., 1333 South Park Street, Apartment 1618, Halifax, Nova Scotia, B3J 2K9, Canada.

REHABILITATION GAZETTE

1982 VOLUME 25

The Current Development of

TECHNOLOGY SERVICE DELIVERY SYSTEMS

for Disabled Individuals of All Ages and Varying Levels of Intervention Needed for Technological Assistance

AGE OF PERSON	low	moderate	high
65+	▨	☐	☐
22 to 64	☐	▨	☐
0 to 21	☐	☐	▨

LEVEL OF INTERVENTION NEEDED FOR TECHNOLOGICAL ASSISTANCE

▨ = Technology Service Delivery System(s) exist or are emerging to address this combination of age and need.

☐ = Absence of Technology Service Delivery System to address this combination of age and need.

Note: It is assumed that each individual included here needs assistive technology. The chart demonstrates the varying levels of intervention required to ensure the individual can adequately access the technology he/she needs.

STATEMENT OF A. GRAY COLLINS

SENIOR VICE PRESIDENT, EXTERNAL AFFAIRS
BELL ATLANTIC CORPORATION

Before the Subcommittee on the Handicapped

Committee on Labor and Human Resources

UNITED STATES SENATE

May 19, 1988

More than seventy years ago, Theodore Vail created a vision for this country's telephone network: universal service. He believed that the telephone's value grew as the number of subscribers increased. The more people you could contact with the telephone, the more valuable and important the network became.

Over the years, Bell Atlantic and its predecessor companies have worked hard to make Theodore Vail's vision of universal service a reality for all persons, including hearing impaired and disabled customers. Starting with the invention of the artificial larynx in 1929, the former Bell System introduced a number of devices, such as specialized receivers and hearing-aid compatible handsets, to permit as many people as possible to use the network. Today, the Bell Atlantic telephone companies provide special rates and services to the hearing impaired, including discounts on toll services, special rates in some jurisdictions for local service, free directory service, and specially adapted Emergency 911 services.

Bell Atlantic remains committed to the vision of universal service. In fact, research is now being done by our Bellcore affiliate on a range of new services that could significantly benefit the aged and disabled, enhance their quality of life, and ensure that they have access to the telephone network.

A principle example of such services is the Telecommunications Network for the Deaf (TND) system. Today, when a person with a hearing impairment wants to make a telephone call, he or she must first contact a special operator. The hearing impaired person then types a message which the operator reads and relays to the receiving party. To respond, the receiving party must give his or her message to operator who then transmits it to the hearing impaired person using a special teletype.

TND is an automated means of translating calls made by hearing impaired callers, thereby eliminating the need for a special operator. Using specially designed software, TND permits a hearing impaired person to type messages which are then converted into synthesized speech and transmitted to the hearing telephone user. The hearing person responds orally over the telephone and the process is reversed.

Because today's telephone system uses sophisticated computers to switch calls and maintain network activities, software like the TND system could be put into local telephone computers where it would be accessible to large numbers of people. The telephone company's computers would recognize when a call was coming into a deaf person's home or office and switch on the special TND system.

While still in the early developmental stages, TND is already a promising concept. It has been trialed in a number of locations and was recently demonstrated at Gallaudet College where it received an enthusiastic response from many of the deaf students who saw it. Instead of having their telephone conversations translated by live operators, the TND system offers real privacy for both parties to a conversation and provides the hearing impaired with telephone communications that are quite similar to those routinely used by the hearing population.

Unfortunately, it is unclear whether the restrictions in the AT&T Consent Decree administered by the U. S. District Court under Judge Harold Greene prevent Bell Atlantic from using the technological capabilities of the network to do even more for the hearing impaired and disabled. Bell Atlantic urges the Committee to examine this matter carefully. We believe the restrictions in the AT&T Consent Decree call into question Bell Atlantic's ability to work with manufacturers and others to make many new and useful services available to the public. Further, such restrictions blunt our ability and incentives to invest in new research to make the capabilities of the local network available to all. These are issues of importance not just to our industry but all Americans.

M.I.T.
Room 3-137
Cambridge, MA 02139

HARVARD UNIVERSITY-MASSACHUSETTS INSTITUTE OF TECHNOLOGY
REHABILITATION ENGINEERING CENTER

May 19, 1988

For Inclusion in Record of Hearings of May 19 and 20, 1988

The Honorable Senator Tom Harkin
Chair, Subcommittee on the Handicapped
Committee on Labor and Human Resources
Washington, D.C. 20510

Dear Senator Harkin:

I am writing to comment on a specific aspect of the May 6, 1988 draft of the Assistive Technology Legislation you are presently developing. I am among those who have assisted Philip W. Hamilton of the American Society of Mechanical Engineers in editing the earlier draft. In Title I, Part C Definitions, Paragraph 1, the last sentence specifically "excludes software, devices implanted in the body, and devices that are body-worn such as prostheses and eyeglasses". This restriction should be eliminated because it will prohibit inclusion of some of the most useful and cost-effective assistive technology presently available.

Technology for the handicapped has undergone a revolution in the last decade; the advent of microprocessors and microcomputers has permitted major advances in the flexibility and functionality of devices. At the heart of improvements in wheelchair controllers, devices for the nonvocal, and environmental control systems--for example--is the use of software to shape their functional characteristics. In addition, much assistive technology can now be marketed in the form of software and hardware add-ons for mass market personal computers. This lowers the development time and the final cost to the handicapped user and third-party payers dramatically.

Body-worn devices include not only spectacles and prostheses but also a wide variety of braces; articulated orthotics for limiting abnormal movements and supporting desirable motions; electrical stimulation devices for returning function lost to paralysis; and novel sensors such as blink switches, EMG electrodes, and head-mounted light wands used by the most severely disabled to control electronic systems.

The exclusion of either of these large and vital categories of technology would certainly be countrary to the intent of the legislation.

I appreciate your and your subcommittee's efforts in transferring the fruits of academic and commercial research into the hands of intended users and offer any assistance I might provide in the future. Thank you for your attention.

Sincerely yours,

Michael J. Rosen, Ph.D.
Principal Research Scientist

MJR:ms

cc: Philip W. Hamilton, ASME

The American Society of Mechanical Engineers

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Washington, DC 20006-1202
202-785-3756

Statement of

the Council on Engineering

of

The American Society of Mechanical Engineers

on

Assistive Technology Legislation

Submitted to the

Subcommittee on the Handicapped

Committee on Labor and Human Resources

United States Senate

May 20, 1988

Introduction

The Council on Engineering of the American Society of Mechanical Engineers (ASME) is pleased to provide comments on legislation to improve the availability, delivery and development of assistive technology to benefit persons with disabilities. This statement represents the views of the Council on Engineering rather than an official position of ASME.

The Council on Engineering is the operating arm of ASME which directs the Society's extensive technical activities, including conferences, publications and research. The breadth of these technical activities cover 34 divisions, four Institutes, three interdisciplinary programs, and one of the world's largest technical publishing operations. The activities of ASME and its members include most of the basic and applied technologies relevant to assistive technologies and mechanical engineers represent the majority of engineers involved in developing and manufacturing assistive technology devices. The Society has a biomedical engineering division, a research Transaction Journal on Bioengineering and a Technology Transfer journal, SOMA: Engineering for the Human Body. In addition, several ASME research committees address the issues related to medical devices and human safety.

Need for Assistive Technology

Despite the current rapid pace of scientific and technological change, the extent of the national efforts devoted to assistive technology for disabled persons is minimal in relation to the need. Today there is not a single accredited program for rehabilitation engineering in American universities.

Over 400 million people in the world have severe impairment and 100 million of them cannot function independently. In the United States alone, there are about 28 million people with some degree of musculoskeletal disability. There are over 29 million people in the U.S. over 65 years of age. The aged represent the fastest growing sector of our population.

In 1985, four billion dollars were spent on rehabilitation and an estimated 11 billion will be spent in 1990. Medical instruments and rehabilitation devices have been identified by the U.S. Department of Commerce as one of the emerging technologies which will have an important impact on the U.S. economy (NBSIR 87-3671 November 1987).

Barriers to Commercialization

Despite the need for assistive technology, there are a variety of factors contributing to the slow progress in commercialization of devices, including:

1. High cost: Many devices are patient specific and must be custom made. The resulting high cost limits their market potential and availability.

2. Specialized skills: A limited number of engineers and scientists currently work in the field. Further, it is difficult to attract and coordinate the interdisciplinary skills, which are needed for equipment innovation.

3. Liability: Product liability laws and health and safety regulations frequently discourage the commercialization of devices and/or significantly increase their cost.

4. Resource integration: The development of devices and delivery systems require integration of resources in Federal, State and municipal governments with those in industry, universities, Federal laboratories, hospitals and clinics.

5. Limited research dollars: Because of the barriers described above, many companies have not been willing or able to commit significant research dollars to assistive technologies. Further, university funded research in the field is largely limited to the availability of Federal research dollars.

Recommendations for Federal Legislation

As an engineering society, our expertise is on the research, development and commercialization aspects rather than financing or program administrative matters. However, we support the objectives of Title I of the draft legislation, "Federal Assistance to States for Assistive Technology Services." Improving the mechanisms to select and deliver assistive technology devices will not only expand the availability and use of existing technologies, but help to define the market for new technologies.

With respect to Title II, we support the concept of developing national standards for assistive technology devices. However, these standards should be developed through a national consensus, voluntary standard approach. Where appropriate, Federal agencies could reference these voluntary standards as a means of satisfying regulatory or procurement requirements.

We support the authorization of new centers for assistive technology outlined in the draft bill. Sufficient flexibility should be built into the legislation to allow for alternative approaches to the centers and to accommodate interdisciplinary research and development as well as cooperative research involving industry, universities, nonprofit organizations and government.

We also recommend that the bill call for an assessment of research needs for assistive technology by a professional society or other independent organization. Such an assessment would be very helpful for prioritizing research, and would be an important resource for inter-agency cooperative efforts on research.

An assessment of research needs should also be valuable to Congress to help demonstrate the extent of the needs. As indicated in the above discussion on barriers to commercialization, the Federal government is virtually the only source of funding for university research. The current level of Federal funding is not only inadequate for meeting many research needs, but also for attracting and developing sufficient technical talent and facilities for the longer term.

Finally, because liability problems are a serious deterrent to the commercialization of assistive technology devices, we urge Congress to explore alternative approaches to ameliorating this problem.

We appreciate the opportunity to submit our views on proposed assistive technology legislation, and we hope the subcommittee finds our comments to be helpful.

apta American Physical Therapy Association

May 27, 1988

The Honorable Tom Harkin
Chair, Senate Subcommittee on the Handicapped
United States Senate
Washington, DC 20510

Dear Mr. Chairman:

The American Physical Therapy Association (APTA) commends you on your sponsorship of proposed legislation concerning Assistive Technology for People with Disabilities and we submit the following comments which we request be made a part of the record of the hearings held on May 19-20, 1988. The APTA is a national membership association representing over 47,000 physical therapists, physical therapist assistants and students of physical therapy.

The practice of physical therapy involves the evaluation and treatment of musculoskeletal, neurological, pulmonary and cardiovascular systems, with the goal of restoring optimal movement and function. Many of the patients who are treated by physical therapists are those who have disabilities.

In addition to taking this opportunity to express our support for this bill, we also welcome the chance to bring to your attention a small but troublesome area in which no coverage currently exists and one which proves especially problematic to persons with disabilities.

Since the beginning, or at least very near the beginning, of the Medicare program, coverage has been provided for durable medical equipment. This coverage, however, has not extended to bathroom safety equipment. The Health Care Financing Administration has taken the position that, since this equipment is for the purpose of a disabled person's safety rather than for a medical purpose, coverage is not authorized by Congress.

Yet, this equipment clearly can make the difference between disabled persons need for continued institutionalization and their return to a home environment in which they can function. Examples of bathroom safety equipment which is not covered under Medicare include grab bars, bathtub seats, bathtub transfer benches, raised toilet seats and toilet safety rails.

This concern falls very much within the purposes of the proposed legislation to facilitate the delivery of assistive technology to people with disabilities. Consequently, we urge that the portion of the legislation which deals with Federal reimbursement programs specifically address this problem by amending existing Medicare coverage of durable medical equipment to include such items as bathroom safety equipment.

1111 North Fairfax Street Alexandria Virginia 22314 (703) 684 APTA

We appreciate your efforts to provide assistance to persons with disabilities and we look forward to working with you toward this end.

Sincerely,

Pamela Phillips

Pamela Phillips
Associate Director, Government Affairs

PP/pw

NRH
NATIONAL
REHABILITATION
HOSPITAL

102 Irving Street, NW
Washington, DC 20010-2949
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MEDLANTIC

May 23, 1988

Honorable Tom Harkin
Chairman
Subcommittee on the Handicapped
113 Hart Senate Office Building
Washington, D.C. 20510

Dear Senator Harkin,

It was an honor meeting you at the hearings on assistive devices for disabled persons last week. I was very impressed with the obvious commitment of you and your staff in addressing the important issues concerning the dissemination of rehabilitation technologies to persons with disabilities. As I indicated to you at that time, I will be glad to do all that I can to assist you in developing the strongest bill possible.

I have been asked by Mr. Silverstein of your staff to provide written comments on the financing of assistive devices. Please note that the following comments do not necessarily represent the views of the National Rehabilitation Hospital, where I serve as Program Manager for Health Services Research. I hope that you will accept them as the views of one physically disabled researcher who specializes in the financing of medical rehabilitation, rehabilitation engineering, and other services for the disabled population. I have attached my resume to indicate my credentials to comment on these issues.

The following comments relate to the financing of devices that have already been designed, developed, and manufactured, but still need to be provided, learned, and maintained by disabled persons. The issues that I address, which are most closely related to your proposed bill, are somewhat different than the financing issues concerning the design, development and manufacturing of assistive devices, including so-called "orphan technologies" that have very small potential markets. I would be glad to discuss those other issues with your staff at a later time.

The current health care financing "system" in this country does not adequately provide access to affordable assistive devices for disabled persons. There are several reasons for this lack of access, some of which are not subject to ready amelioration without fundamental changes in the system. Recognizing that fundamental changes in the health care financing system are unlikely in the current political and economic environment, the following comments address current impediments to the wide dissemination of assistive devices under existing programs, and long- and short-term approaches to addressing these impediments.

The current system of health care financing is highly fragmented, consisting of a multitude of public and private sector insurance programs with a variety of different eligibility rules, coverage rules, and payment mechanisms. Medicare, Medicaid and the VA programs have complex eligibility rules that often preclude eligibility for disabled persons. Private sector insurance programs are primarily employment-based, and coverage can be lost during times of illness when employment and financial resources are lost. Because these programs are poorly coordinated, disabled persons requiring assistive devices often "fall between the cracks of the system." Even if a disabled person is covered under a program, few programs cover assistive devices and their repair.

The private sector insurance plans, in particular, are unlikely to provide adequate coverage of assistive devices. This is because private sector plans, such as Blue Cross/Blue Shield, other health insurance plans, and HMOs, are in competition with each other to provide the most attractive package of services and premiums to their general membership. By covering a broad range of assistive devices designed for disabled persons, a plan is likely to attract a large number of disabled enrollees. However, because disabled enrollees tend to be much more intensive users of health care services than the general population, and because the assistive devices and other services needed by disabled persons are often very expensive, the plan that enrolls a large number of disabled persons will incur higher costs than its competitors and thus become less competitive. For this reason, private sector insurers have a strong incentive not to cover assistive devices and other services for disabled persons.

The tendency for a private insurance plan or HMO to attempt to discourage high risk persons from enrolling is often referred to as "preferred risk selection." The tendency for low risk persons to avoid enrolling in plans with benefits they do not currently need (and thus high premiums) is called "adverse selection." For example, HMOs very seldom cover assistive devices, and it is often alleged that they have this policy to discourage disabled persons from enrolling. They instead tend to cover services that will be attractive to a young, healthy, non-disabled population such as "wellness care" and "prenatal care."

Issues concerning our fragmented financing system, preferred risk selection, and adverse selection are best addressed in a systematic manner through a comprehensive financing approach. Ideally, this would mean the development of a well coordinated national health insurance program devised to ensure efficiency through a comprehensive organizational scheme and decentralized provision of services. Such a system has been designed by Professor Enthoven at Stanford, and has been incorporated, in part, into a number of Congressional bills. However, recognizing that development and implementation of such a system is probably not currently feasible politically, it is necessary to determine what incremental steps to take to modify the current system.

The following are several suggestions concerning modifications to the current financing system:

1. Medicare - The Medicare program currently covers assistive devices that are "medically necessary," such as wheelchairs and braces. HCFA has tended to interpret this statutory term narrowly to disallow certain devices that could be considered medical necessities under a broader interpretation. For example, it does not cover communication aids and environmental control systems. To address this problem, either the definition of "medically necessary" under the Medicare program could be expanded or an alternative terminology relating to the disabled population such as the term "functionally necessary" could be added. This term would, of course, have to be carefully defined.

   In addition, Medicare does not explicitly cover rehabilitation engineering services that are necessary to assess, develop, and/or adapt assistive devices to the needs of the individual disabled person. Without such services provided by a trained rehabilitation engineer, many devices that have been developed would be virtually useless to many disabled persons. Rehabilitation engineering services could be explicitly covered under the program.

2. Medicaid - The provision of assistive devices is currently an optional service under the federal Medicaid program. Therefore, states are not

required to provide and repair assistive devices under their state Medicaid plans, and most have chosen either not to cover such services or to use a narrow interpretation of "medically necessary" devices, similar to the Medicare program. As with the Medicare program, state Medicaid programs could be required to pay for assistive devices, the adaptation of assistive devices by rehabilitation engineers, the training of disabled persons on the devices, and the repair of such devices.

3. Veterans Administration Programs - The V.A. has generally provided an excellent example of what the federal government can achieve in terms of providing assistive devices to disabled persons, at least with respect to the basic needs of persons with service-connected disabilities (Category A Veterans). It would be valuable to examine whether Category B and C veterans with non-service-related disabilities are similarly receiving the assistive devices and related services they need. It would also be valuable to examine the mechanisms by which newly developed devices are provided by the V.A. system, and whether such new technologies are being adequately incorporated into the lives of disabled veterans.

4. Vocational Rehabilitation Agencies - State V.R.A.s that receive funding under the federal Rehabilitation Act pay for some assistive devices that are likely to enhance the employment capability of potentially employable disabled persons. However, such agencies are typically poorly funded, and little money is available for the provision, training, adaptation, and repair of assistive devices. Additional funds under the Rehabilitation Act could be specifically set aside for these purposes.

5. Private Sector Health Insurers and HMOs - As indicated above, the decision of whether private sector health insurers and HMOs will cover assistive devices is complicated by issues of preferred risk selection and adverse selection. Health insurers and HMOs are currently deterred from covering such devices and related services for fear that they will become less economically competitive by doing so. It is therefore necessary to create a "more level playing field" for health insurers such as Blue Cross/Blue Shield that pay for (at least some) assistive devices. This could be done most directly and easily by mandating the

provision of assistive devices. However, given the current political controversy over mandating health care benefits, it may be preferable to simply subsidize (possibly through the tax laws) insurers that provide such coverage.

6. The Disabled Individual (under private health insurance) - Even if a disabled person has an insurance policy that covers certain assistive devices, almost all policies have significant deductibles and copayments that are the financial responsibility of the enrollee. As a personal example, my electric wheelchair that had to be custom-adapted with a chin control and a recliner mechanism cost $10,000. Blue Cross/Blue Shield, which requires a co-payment of 20% on durable medical equipment, paid approximately $8,000 for the wheelchair, leaving me with a bill of approximately $2,000 above the annual $200 deductible. It should be noted that Blue Cross/Blue Shield is one of the most generous private sector programs available in terms of assistive devices that are medically necessary. Fortunately, I am in a position to pay for my share of such equipment (although it is financially burdensome), but many disabled persons are not.

7. The Disabled Individual (under federal tax law) - The recent Tax Reform Act increased the percentage of income above which medical costs may be deducted. This modification has had a disproportionate effect on persons with disabilities who tend to have high medically-related costs, including the costs of health care and assistive devices (if not covered by insurance), the copayments associated with such services (if they are covered), and the high costs of personal attendant care. There should be some offset for disabled persons to reduce the burden imposed by the tax law. One possibility for such an offset is the creation of a tax credit for assistive devices. Alternatively, the current limitation on the deductibility of medical costs could be waived with regard to assistive devices, their adaptation, and their repair.

8. The Disabled Individual (under SSI and Medicaid) - The above treatment of disabled persons applies primarily to disabled persons who are employed and have private insurance coverage. Disabled persons who are potentially eligible for SSI and Medicaid may compromise their eligibility if they accumulate

resources above that allowed under those programs. This limit prevents the individual from accumulating enough money to purchase the expensive devices (that are not covered by Medicaid) that could assist the individual to become more self-sufficient and employable. This problem could be addressed through a provision in the SSI and Medicaid eligibility rules that would permit the creation by SSI and Medicaid recipients of "assistive device trust funds" that would be exempt from the resource eligibility limits.

9. For-Profit Employers - Employers in the for-profit sector could be encouraged to employ disabled persons and to provide them with assistive devices through further modification of the tax laws. The current tax credit available for worksite accessibility could be expanded in amount and directed explicitly to assistive devices. For example, a one time credit to employers of a maximum of $10,000 per disabled employee could be applied, with the added condition that the device would become the property of the disabled person if employment terminates. A lifetime maximum per disabled person might be necessary to prevent abuse of this credit by disabled persons.

10. Non-Profit Employers - Employers in the not-for-profit sector could be encouraged to employ disabled persons and to provide them with assistive devices through federal grants for assistive devices. Such grants could be administered through the Rehabilitation Act, and could use cost-sharing arrangements with State government, local government, and/or the non-profit employer.

Several themes run throughout the above policy suggestions. First, any policy must define carefully what it means by assistive devices, since assistive devices encompass a very broad scope of technologies that benefit disabled persons. Many of these technologies are not "medical" or "medically necessary" according to the narrow definitions applied by the IRS, Medicare and Medicaid, but are nonetheless essential to reducing the functional limitations of disabled persons. Thus, the proposed bill should consider broadening the definitions used by these programs to incorporate the concept of "reduction of functional limitation."

Second, policies that simply finance the purchase of assistive devices for disabled persons are not sufficient. The policies must also address the financing of rehabilitation engineering services necessary to assess the needs of disabled persons and to adapt the technologies to those needs; the financing of the training of disabled person to use the assistive devices; and the financing of the repair and maintenance of assistive devices. Without such services, the devices are likely to be provided inappropriately, used inappropriately, and/or abandoned.

Third, the various payors and programs addressed above should be coordinated to the extent possible to prevent the duplication of expenditures. It is necessary to determine which program is primarily responsible for the financing of the assistive devices for any particular individual, and the relative obligations of other programs. Private sector programs, in particular, should be discouraged from imposing the full obligation on the public sector and from engaging in preferred risk selection.

Fourth, since the financing of assistive devices and related services through this bill would enhance their effective demand, and thereby increase their cost, it will be necessary to include provisions in the bill to contain these costs. This can be achieved most effectively by using the federal government's leverage through its purchasing power to buy these devices and to enhance the competition among suppliers and providers in furnishing these devices. Eventually, it will also be valuable to address the effects of potential legal liability (and liability insurance) on the costs of assistive devices. This issue is currently being studied through grants by NIDRR, Department of Education.

Finally, in response to your request at the hearings for documentation of the cost-effectiveness of assistive devices, I am not aware of any such studies that have been conducted. However, substantial anecdotal evidence taken from the experience of disabled persons strongly suggests significant government savings and other economic benefits resulting from the use of assistive devices. From my own perspective, I doubt that I would have been able to receive a J.D. from Harvard Law School, a M.S. from Stanford Medical School, and a B.S. from the University of California without the assistance of my electric wheelchair, reading stands, mouthsticks, and adapted typewriter. I am now able to pursue my career in rehabilitation research (and to write this letter) with the assistance of an adapted computer and a mouthstick. Formal cost-effectiveness studies of assistive devices are badly needed, and could be encouraged through the Rehabilitation Act.

If I can be of further assistance to you and your staff, please do not hesitate to contact me at (202) 269-8373 (work) or (202) 863-2783 (home). In addition, I would be happy to demonstrate to you how I have adapted my home in Southwest Washington and my office at Capitol Hill Hospital to meet the needs associated with my physical disability. I strongly support your efforts in this important area, and I hope that the bill is well received by Congress.

Sincerely,

Drew Batavia, J.D., M.S.
Program Manager for
Health Services Research

cc: Gerben DeJong, Ph.D.
Edward A. Eckenhoff, M.H.A.
Guy S. Hammer, B.S.E.E., P.E.
Samuel McFarland, M.S.M.E.
James Reswick, Sc.D.
Lawrence Scadden, Ph.D.
Virginia W. Stern, M.A.
Steven C. White, Ph.D.

The University of Iowa
Iowa City, Iowa 52242

1847

Division of Developmental Disabilities
Department of Pediatrics
University Hospital School

May 9, 1988

Rud Turnbull, Ph.D.
Senate Subcommittee on the Handicapped
SH 113 Hart Senate Office Building
Washington, D.C. 20510

Dear Dr. Turnbull:

You will find enclosed brief descriptions of four persons with disabilities here, in Iowa, who need assistive devices for optimum functioning. As you will see, in some instances these summaries relate a "success story." However, there also is included some instances of problems in the systems for providing services and support for persons who are disabled.

It is my understanding that these descriptions may be read into the proceedings of the hearings. You will note that the people's names are mentioned, and we have obtained permission from the individual, his or her parents, or other authorized representative, to use their names for that purpose. Of course, please feel free to edit these descriptions in any way that makes them more suitable.

Sincerely yours,

James C Hardy

James C. Hardy, Ph.D.
Director of Professional Service

cc: Alfred Healy
Al Guida

Profile: *Deb Arguello*
1613 North Shore Drive
Clear Lake, IA 50428

Deb Arguello is a 17-year-old Iowan with cerebral palsy. She is bright, energetic, and determined to be as independent as she possibly can. Deb recently received her new power wheelchair which has her communication systems (electronic communication aid and manual language board) integrated with it. The development of this integrated unit by the staff of the Inpatient Unit at University Hospital School, University of Iowa, is an excellent example of assistive technology service delivery.

Deb's functional and efficient work space is somewhat limited by her cerebral palsy. She has found through many years of experience using her language board with her laptray and manual wheelchair, that use of her left hand is best when she can fully extend her left arm while keeping her right hand pressed underneath the laptray for increased stability. This made it necessary for the Inpatient Unit staff to carefully determine positions for the joystick controller of Deb's new power wheelchair and the Touch Talker electronic communication aid so that both devices were optimally accessible and efficiently useable by her.

Deb was first properly positioned in the new power wheelchair. It was then found that the position of the joystick using the standard mounting bracket would not work for her; the joystick had to be mounted higher and more to the center than the bracket would allow. Also, it was found that Deb was able to access the flat keyboard of the Touch Talker, if the lower part of the keyboard was flush with the surface of the laptray while the rest of the keyboard was allowed to slope gently upward and away from Deb. This meant that the Touch Talker could not just sit on the top of the laptray. These requirements were eventually met by the rehabilitation engineering staff in close cooperation with Deb, an occupational therapist, a physical therapist, and a speech pathologist. First, the standard joystick mounting bracket was modified so that the joystick could be properly positioned. Next, a custom laptray was developed that integrated the special joystick position, the special Touch Talker position (which required the device to be partially recessed into the laptray) and the ability to replace the Touch Talker with Deb's language board as needed. The laptray also had to be designed to take some hard knocks as Deb learns to drive the power wheelchair. Although the laptray was developed specifically to address Deb's needs, it incorporates a number of features that will be very useful to many of the patient seen at University Hospital School. As such, this project is also an example of a patient-centered approach toward research and development in which the problems studied and solved arise directly from patient needs.

Profile: *Rex Bunger*
Route 1
Janesville, IA 50647

Rex Bunger, 32, is a client at the Adults Care, Incorporated Center for Community Integration in Waverly, Iowa. He is severely disabled with cerebral palsy, and has almost no control over the movements of his body. Rex cannot speak, and this has meant that accurately determining his intellectual abilities is very difficult.

"Rex is a perfect example of a person who has a lot of intelligence," explains his case manager, Dennis Kolpek, "and his memory is exceptional." Findings ways for Rex to use this intelligence to interact with his environment has been difficult.

Following high school, Rex was a client at the Adults Care Key VII center in Waterloo. An important step forward for him occurred when staff there realized Rex could use a chin-operated microswitch. With this switch, Rex was able to work in the center's wood working shop, where he served as a sort of safety monitor for other employees in the shop. If, for example, an employee neglected to wear safety glasses while using a power saw, Rex could use the microswitch to turn off the equipment.

Being able to actively participate has been very important for Rex, as it would be for any of us. But the limitations on his ability to interact, and, particularly, to communicate, are incredibly frustrating for both Rex and for the staff. "His current language board is just too slow and too limiting," says Kolpek.

So new technologies are being investigated, and there are hopes that a new computer system, operated by a combination of head and arm switches, will allow Rex a form of communication better suited to his abilities.

But communication devices are expensive, and Kolpek points out, accessing the funds for such a system can be very difficult. A speech pathologist has identified an appropriate communication system for Rex, but acquiring funding has so far proven to be a stumbling block. For the time being, Rex is waiting, as he has been for the past 15 to 20 years. Kolpek is optimistic that funds will be found, and that the new computer, with its voice component and its greatly increased speed, will allow Rex to interact with his world in ways that have never been possible before. "For Rex, with this computer, even supported work, out in the community, may be a possibility," says Kolpek.

Kolpek is as enthusiastic about the prospects that such a device offers as Rex is. "He is a unique person," says Kolpek. "To put it simply, I really want to hear what he has to tell us."

Profile: *Ron Grooms*
104 Computation Center
Iowa State University
Ames, IA 50011
515/294-1979 (work; afternoons) 515/292-1446 (home)

Ron Grooms both uses and designs adaptive technology. Grooms was disabled while a graduate student at Iowa State University. He has quadriplegia, with paralysis of his arms and legs, but he retains limited movements in his hands. Today, he is a Specialist for Research and Development in the Disabled Users' Services at the Iowa State University Computation Center in Ames. Among other things, Grooms works with technology issues, with studies in artificial intelligence, and with the design of adaptive computer software for persons with disabilities. "My undergraduate studies were in electrical engineering," Grooms explains. "As a graduate student, I was the first research assistant in what was then the newly formed Computation Center at ISU." About a year after he completed his studies, he was appointed an instructor in computer sciences, and he has now worked in computers for some 25 years.

His employer, ISU, has made Groom's work place accessible by means of a variety of both high and low technology. Entrances to the building now have doors that open automatically. Inside, door handles were installed that open by an upward, rather than downward motion--a necessity, Grooms points out, for a person whose triceps, (the muscles that allow the hand to push down) aren't functional. Grooms has a specially adapted desk that he points out as an excellent example of "low" technology. Adapting it was a matter of raising it up on stable wooden blocks. All of these changes make it easier for Grooms to follow the career he has chosen.

He not only enjoys his work, he serves as a source of expert information in the field of adaptive computer technology for people from throughout the country. But there is an ironic side to all of this, for being self-supporting is, in actuality, a mixed blessing for Grooms.

"If you have an average or better income," he explains, "there is no place for you to get financial help. My standard of living could be better, if I didn't work." Grooms faces significant expenses not just for the technology he needs, like his wheelchair, but also for the daily attendant care that allows him to be independent.

For the past 21 years, Grooms has had the same live-in attendant to provide personal care and to accompany his to his job. But this long-time attendant is now becoming elderly, and Grooms knows that he will soon have to begin the search for a new attendant.

Because of his income, Grooms gets no help with the expenses of attendant care outside of a tax deduction. "People offer to come work for me for $200 a week plus room and board and every weekend off," he explains. "That simply isn't possible for me."

Persons who are not gainfully employed are eligible for a range of benefits that may include funds for necessary technology, such as wheelchairs, and for the hiring of attendants who provide personal care. Persons who are gainfully employed, and who thus do not receive benefits, often find the costs of medical care, assistive devices, and attendant care to be staggering. Some will be lucky enough to have insurance to help out. Many others will not, or will, like Grooms, find that insurance helps with some, but not a major portion, of their expenses.

"I see this as a major problem--the major problem--right now," say Grooms emphatically. "This is the age of the agency; the solution if your neighbor is hurt is not that you help out. The solution is that you pay taxes to get an agency to do it. Except that people slip through the cracks."

Profile: *Michael Vogeler*
RR #2, Box 71
Vinton, IA 52349

Michael Vogeler, 12, is a young Iowan with cerebral palsy who lives with his parents, Carl and Valerie. Mike and his family enjoy getting out and about, and have come to rely on various mobility systems (wheelchairs, etc.) over the years to help them accomplish these outings. Mobility for Michael, especially independent power mobility, has presented some challenges to the Vogeler's. These challenges have included funding issues as well as the availability of information they need to be informed consumers of assistive technology.

The first real obstacle that the Vogeler's confronted occurred when Mike was younger. They wanted to order a manual wheelchair, but had to wait for prior approval from their insurance carrier before they could purchase the chair. By the time approval was obtained and the chair received (some 7 months later), Mike had grown out of that size wheelchair. Wheelchairs designed to "grow" with a child were not yet available.

The next set of challenges occurred when the Vogeler's found out that Mike could benefit from the increased independence of powered mobility. The family eventually decided that a Fortress 3-wheel power chair (also known as a 3-wheel scooter) would work for them. "As we ordered Mike's scooter, we decided to bypass the prior approval idea, ordered and paid for the scooter ourselves, and four years later, the insurance company is still decided whether they are going to contribute or not," says Mrs. Vogeler. "But Mike has been able to benefit from power mobility despite prior approval."

Once they got the scooter home, the family found that it was becoming a problem to get it around corners and in and out of rooms. The Vogeler's tried to get some help on remodeling from local contractors, but to no avail. They then contacted the Assistive Devices Information

Network, which is a service of Iowa's University Affiliated Program that offers assistance to anyone seeking information on assistive technology. The information specialist at the Network put them in touch with local consultants on barrier-free designs in homes and buildings. As Mrs. Vogeler explains, "We took action on the information provided by the consultants and got workable, yet aesthetically pleasing, changes made to our home. We are very pleased with the results.

The Vogeler's continue to use the Network to increase their "consumer awareness" of options that will meet their needs. The family is now looking into wheelchair lifts for vans and appropriate wheelchair restraints that would allow Mike to ride in the scooter while traveling in the family van. They were especially concerned about the restraints after reading an article on safe transportation of persons with disabilities in a recent Assistive Devices Information Network Newsletter, which is an information dissemination tool of the Network. The Vogeler's contacted the Network to find out what options there were for securing the scooter in their van. The information specialist contacted the manufacturer only to learn that the manufacturer does not recommend any restraint system for its 3-wheel power chair, apparently because of liability issues. The manufacturer could only say that they were aware of one or two types of restraining systems being used by people around the country.

The Vogeler's are still exploring options for van lifts and restraints for the scooter. Since these items are very expensive, they will also be exploring funding options, if those options exist. Given their previous experience in these matters, they are approaching this next challenge with some trepidation.

Rte 6, Box 663
Moulton, Alabama
35650

THE NEED FOR INDEPENDENCE

by Daryl L. Smith

When my brother was eighteen he did it the usual way. After training for a job, he went away from home to find work. A year later, he brought his future wife home to meet our parents. A couple of years after that, he and his wife brought their new son home to meet his grandparents and me, his uncle. But I was different.

I spent my fourth, fifth, and sixth summers exploring the orchards, fields, and vineyards of Michigan, where my parents migrated each year to work. When we returned home to the Tennessee Valley of rural North Alabama at the end of the third summer, I was six years old, and it was time for me to start school. For as long as I could remember I had watched my brother climb onto the big yellow schoolbus each morning and ride away leaving me behind, so when my turn came, I was ready. My best friend rode the same bus. Together we had explored the farms of Michigan; now, together, we entered the first grade. It was a good year. The next summer, our parents decided to stay in Alabama.

That summer, something in my body went terribly wrong. Instead of turning tan as it always had when exposed to the hot Alabama sun, my skin burned deeply. By the end of summer, when it was time to return to school, my muscles were so weak that I needed help from friends in order to climb the two flights of stairs to my classroom. After a few weeks, my second grade teacher asked my parents to take me out of school. She said she was afraid for my safety (because of my weakened condition I might fall on the stairs, etc.), but some of our neighbors prevented their kids from coming near me because of my strange disease, and they warned other parents to do the same. So I suspect she had some help in making her decision.

The doctors in Alabama didn't know what was wrong, so my parents took me to the Mayo Clinic in Rochester, Minnesota. Doctors there identified my disease as the childhood form of dermatomyositis. They said it was an extremely rare skin and muscle infection, but they didn't know the cause, and at that time there was no treatment. (Today, it is known to be a malfunction in the auto-immune system. My own body's immune system was destroying its skin and muscle.) Before we left Mayo, my parents were told that I would possibly die within a few years.

Instead, during the next ten years my muscles and skin continued to deteriorate under the attack of dermatomyositis. During these years, the condition of my skin was unspeakable. Around the age of twelve my eyelids were severely damaged, leaving my eyes constantly exposed to light, air, and dust. Slowly, my corneas began to scar, and I went blind. During these years my muscles got smaller and smaller. This caused contractures in my legs, arms, and hands, which got more and more severe. By the time I was eight I could no longer walk. By the age of ten I could no longer sit up. When I was seventeen, two things occurred simultaneously; I went through puberty, and the disease went away. But the consequences of the disease remained.

I was able to turn over by myself and feed myself, but that was *all* I could do for myself. Everything else had to be done for me in bed by my mother. So when I was eighteen, instead of becoming independent like my brother, I was more dependent on my parents than ever. Still, I had an aching desire to be free and independent, free to travel, to meet new people, to try new experiences, to make my own decisions and my own way in life. But when I was eighteen there was no way.

My days and nights were empty and lonely, as they had been for years. In the mornings my bed would be rolled into the living room where I watched, then in later years listened to, television. There was nothing else to do.

My parents didn't have time to read to me, and there was no one else to do it. At night, my bed would be rolled back into the bedroom.

I had very few visitors, and most of them were older people. I rarely saw kids my own age. Some stayed away because they had been taught to fear me. Their parents believed for years that my disease was contagious, in spite of the fact that no one else caught it and the doctors at Mayo said that it was not. Others (like my best friend) stayed away because seeing me caused them to be depressed. There were a few visitors my own age, but age was about all we had in common. They talked about school, playing ball, and dating. I was envious. I talked about politics, sports, and world events straight from television. They were bored. So I suppose most of the kids stayed away because visiting me wasn't much fun. When I thought about kids my own age, especially the ones I went through the first grade with, I hated them. I hated them for going on with life without me.

My religious visitors told me that my illness served some divine purpose, but since I had been neither consulted nor informed by God about this purpose, I hated Him, too. These latter visitors often commented about my cheerfulness and positive attitude, but they saw only the surface. Inside I was full of bitterness, envy, and hate. These feelings came more from the isolation and loneliness than from the direct physical effects of the disease. Living in a rural area where friends often live miles apart made the isolation worse. Here, people met at school, church, and other places where I couldn't go.

The human mind cannot tolerate so much nothingness and loneliness, so when I was very young I learned to escape through imagination. In my fantasy world, I was free to do anything I wished. I flew planes, sailed ships, and commanded armies. As Roy Rogers, I defended the ranch agin' Indian attacks. I lived vicariously all of the adventures I saw and heard on television. I explored jungles, climbed mountains, and landed on the moon. But more than anything else, I lived for football season when I could listen to the Auburn University games on the radio. From the announcer's description I set up the offensive and defensive formations on the ceiling, then I carried out the play. During the following week I replayed the game over and over, with myself in the starring role. As I got older, girls entered my fantasy world, and they all willingly surrendered to my passionate desires.

When I was twenty-three I discovered Talking Books, books and magazines recorded on records and made available to the blind and physically handicapped by the Library of Congress.

SEARCHING

By the time I was twenty-seven years old, I had spent twenty years hopelessly dependent on my parents for my every need. The first ten years had been a daily struggle against dermatomyositis just to stay alive. The second ten years had been a daily search for something, anything to do. I had wanted to find a way to repair some of the damage that had been done to my body, but there was no rehabilitation program or physical therapy available. I had wanted to learn, but teachers for the homebound in rural Lawrence County were, and still are, not available. There was no one else to teach me anything, with one exception. When I was eighteen years old, I listened to a class in amateur radio theory on educational television. Then, with the help of two old friends of my dad, I took a test and received my ham radio license. During those twenty years, that was the only thing I was able to do for myself that had any effect on the course of my life. By the summer of 1973, I was spending two or three hours a day talking with friends by radio and listening to Talking Books. But most of the day I still spent in impossible fantasies.

Then, one late summer evening came the first of three events in as many months which turned my life around and led me out of that stagnant existence. I heard on the news that Calhoun Community College in Decatur was going to offer a course by newspaper, with one lesson being printed each week in *The*

Decatur Daily. The course was called "America and the Future of Man." The next morning I called Calhoun, and after explaining to three people, including the switchboard operator, that I wanted to sign up for "America and the Future of Man," I was turned over to Jim Burr. I explained it again to him. 'Mr. Burr said, "Fine, that will be $22. Come over to the registrar's office and sign up." I asked, "Can I sign up without coming over there? You see, I have a physical handicap which confines me to bed, and I live twenty miles away, in Moulton." He said, "Certainly, I would be happy to register for you. Just send me a check for $22. And then, if you'll give me your mailing address, I'll send you the extra reading material so you can go ahead and get started." That came as a shock. "What extra reading material?" I asked. "I thought there would just be one lecture a week, printed in the newspaper." "That's true," Mr. Burr replied. "But for each lecture there are two or three articles that you need to read." Feeling swamped, I said, "I may not be able to handle the course after all. Besides being confined to bed, I'm blind. I thought I could get someone to read one article a week." Mr. Burr asked if I had gotten through high school by reading Braille. Now, feeling hemmed in, I decided to confess everything. "No sir," I said. "My hands are drawn into the shape of a fist, so I can't extend my fingers far enough to use Braille. And, well, I didn't finish high school; in fact, I had to drop out after the first grade, twenty years ago. So I never learned to read at all. Most of my education has come from television." By that time, an ordinary man would have been ready to hang up on me. "By Golly!" Mr. Burr exploded, "If you want to learn *that* bad, we'll find a way!" And together, we did.

Before we hung up, Mr. Burr volunteered to record all of the material for me on cassette tape, and to tutor me one day a week by telephone. Within a week, I had the first cassette. Mother placed it in my tape player and put the player by my left side on the bed. I was able to operate the player with a stick about the size of a pencil, which I held in both hands to get enough leverage to depress the buttons. In this way, I could study the tape for several hours without any further assistance. As predictable as the sunrise, Mr. Burr would call each Monday morning at 7:30 sharp to discuss that week's lesson.

At that time, I could not use the phone without help. In order for me to use it, Mother would place the receiver over my ear and mouth, then put the cord between the fingers and thumb of my right hand so that I could hold it in place. I had no idea that I would ever be able to use the telephone without any help from anyone. However, within two years, I would.

In the Fall of '73, the second event took place. During the course, I spent five and a half weeks in Huntsville Hospital for plastic surgery. The doctors had been telling me for years that my blindness was due to damaged eyelids, yet as my eyes continued to deteriorate, the opthamologist continued to refuse my request to be referred to a plastic surgeon. He said, "In your case it would be a waste of time and money. Plastic surgery is impossible, due to the amount of scar tissue." However, with the help of a nurse friend, I found a doctor in Huntsville who believed my eyelids could be repaired. A year and four skin grafts later, they were almost as good as new. It was too late to save my vision, but a constant source of irritation had been eliminated. Of course my physical appearance was improved, and this was a great boost to my self-image.

A couple of days after I entered the hospital for the first skin graft, the third event took place. I had asked for a special room which had been equipped by NASA (as a public relations project) with an environmental-control system. A man named San-car dropped in to inform me that he had just started a small company that would manufacture environmental-control systems called (appropriately) Nu-Life Systems, and he asked if I would like to have such a system in my home. He said they could tailor the system to fit my own personal needs. If I wished, I could operate a speaker phone--turn it on, dial a number, turn it off; operate a remote-controlled tape recorder;

communicate via an intercom; turn on and off my air conditioner, Talking Book machine, and television; and control virtually any electronic device in my room. He said I could operate this electronic marvel by moving only one finger a fraction of an inch. He was talking to a person who was almost completely helpless--dependent on others for every need. He was offering me a miracle, a degree of freedom I had never hoped for outside of my fantasies. Yes, I would like to have such a system. Then came the bad news; it would cost three or four thousand dollars. I didn't have that kind of money, but I started looking. Early in the next year when I entered the hospital for the second skin graft, Barry Stephens, my Vocational Rehabilitation Service counselor at that time, drove over to see the environmental-control system. When he saw the independence that I could achieve with such a system, he strongly supported my desire to have it in my room at home. A few months later, he signed me up as an active VRS client. This committed the VRS to deal with me (as they had never been willing to do before) as a potentially productive member of society. A year later, in the spring of '75, they agreed to pay for my college education and to buy a Nu-Life System for my room.

Meanwhile, I had completed the course on "America and the Future of Man," and had earned a B. Mr. Burr encouraged me to take another course. Since he was a political science instructor, he offered to teach me one quarter of Comparative Government; again, we were talking on the phone one day a week. The rest of the time I was listening to the textbook, which he had recorded for me. We compared the governments of the United States, England, France, West Germany, and the Soviet Union. It was a standard college course taught over the standard length of time, but my ability to study hadn't caught up with the standard pace. By the end of the quarter all five governments were beginning to look alike to me, and frankly, I didn't care who did what. Nevertheless, Mr. Burr gave me a B for the course. It was a subjective grade, and I objected. I felt I deserved less than a B, and I told him so. I continued to tell him so for five or ten minutes, when he stopped me by saying, "Damn it! What do you want me to give you, an F?" Coming from the man I had learned to respect so much, this was a valuable rebuke. It helped me to realize that I was worthy of being rewarded for the hard work I had put into the course.

Mr. Burr decided that if I was going to learn at Calhoun, I needed to be exposed to the views and ideas of as many different instructors as possible. At the same time, If I could make the grade with them, it would build my self-confidence. Mr. Peters, another political science instructor, offered to take me on for one quarter of American Government. After several months of previewing the course with Mr. Burr, I took it. Mr. Peters gave me an A for the course, and this time I didn't object.

This was the winter of '75. I had been a student for a year-and-a-half, and American Government was only my third course. Things had been moving very slowly. That spring, my Nu-Life System arrived. Now that I was able to use the telephone without help and make notes with my remote-controlled tape recorder, things began to speed up. By the spring of '76 I had thirty-six hours of credit, and it looked like I was going to be able to continue at Calhoun long enough to get an Associate's Degree in General Education. But, there was a problem.

I was allowed to enter Calhoun without a high school diploma, but without it or its equivalent, the GED, all of my work would be invalidated. I told my problem to a ham radio buddy, Lyle, who was a school teacher in Tuscumbia. He discovered that the test was available on tape from the Department of Education, obtained a copy, and administered it to me. I passed the test, thus becoming a legitimate student.

It was the summer of '76 when I heard a classroom lecture live, for the first time. By then I had enough hours to finish my freshman year. However, I was still going to school by talking to the instructor one day a week and listening to textbooks which I was now receiving from Recordings for the

Blind in New York. During the spring, Mr. Burr and Ms. Greg, my psychology instructor, had collaborated on getting me into the classroom by telephone. By summer they had persuaded the telephone company to install a business-type conference phone in the school, the school to allow the installation, and the VRS to pay for it. So that summer, when I started my sophomore year, I could both hear the instructor and ask questions. I signed up for two courses, and we had both of them moved to the same room for the convenience of the telephone. The first class of the day was General Biology. Each day the instructor, Mr. Williams, would set the phone up himself. Then, during class, he wore a small microphone which allowed me to hear the lecture. Since I was listening over my speaker phone, I was able to record the lectures, then play them back as many times as I wished. With the conference phone, I was able to take any class I wanted, since the instructor didn't have to volunteer the extra time to tutor me one-on-one.

At the end of the spring quarter of '76, on my thirty-second birthday, I graduated from Calhoun with an Associate's Degree in General Education. I attended graduation as I had attended classes--by telephone. But for me, it was not a happy occasion. Since most of my new friends were connected in some way with the school, I knew they would slowly drift away. I wanted to work on a degree in Psychology at the University of Alabama in Birmingham, but my parents objected to my moving. My mother insisted that no one else could take care of me as well as she, and perhaps from the standpoint of my physical needs she was correct. But I had greater needs; again, I was being threatened by isolation. By late summer the situation was beginning to look hopeless, when I was rescued by my Vocational Rehabilitation Service counselor, Bob Owen, and Cheri Shipper, a local newspaper reporter. Mr. Owen had spent a considerable amount of time talking to his superiors about expense versus human potential, in an attempt to get them to pay for my tuition and for the installation of a phoneline to connect my bedroom to Birmingham, eighty miles away. Things were looking bleak, until he was aided in persuading them by a newspaper article in which Ms. Shipper "prematurely" announced the intention of the VRS to pay for the continuation of my education. So that fall, as a junior majoring in Psychology, I was able to attend classes at UAB by telephone just as I had at Calhoun.

Now it's the summer of 1980, and I'm thirty-four years old. In the past seven years I have met many people in, and have come to know something about, the outside world. With this outside contact the old bitterness and depression, which fed on isolation and loneliness, have slowly starved. For the past two years this outside contact has included the people of Birmingham, especially the people connected with UAB. Within a year I will graduate from UAB with a degree in Psychology and a minor in Commercial Writing. At that time I will lose my telephone link with Birmingham, once again becoming isolated in rural Alabama. My parents still do not want me to leave home, but if I'm to avoid again being cut off from all the things I want out of life, I must leave Moulton.

THE NEED FOR INDEPENDENCE

Here, now, I have a comfortable life. My parents take care of my physical needs, and my room is equipped with practically anything I want. But looking toward the future, I see difficulties. My dad is sixty-four years old, and Mother, who is responsible for most of my physical care, is fifty-nine and in poor health. It's clear that in a few years they will no longer be able to take care of themselves, much less handle the added burden of me. By moving to Birmingham now, while I'm still in school, I will have some choice as to the type of environment in which I will live. At first, it might be a rehab facility with other physically handicapped people who are training for work, or some other type of institutional arrangement. Later, after I finish school and find employment, it might be an apartment with a live-in attendant, or preferably, an apartment complex with other handicapped people. There, we could share living expenses, such as the cost of attendant care. On the other hand, if I continue living at home with my parents until the day they are no longer physically and mentally able to take care of me, on that day I will be forced into some other type of living arrangement--probably a nursing home here in Moulton. In the meantime, after graduation, my phone link to Birmingham will be severed, thus cutting me off from my new circle of friends. Also, the opportunity for me to control my own life will be gone, since there is little or no chance for me to find employment here.

Employment is my main goal, because it is the key to self-determination. I want to earn my own way in life like any other self-respecting person. I believe I have something to offer, possibly working with the physically or emotionally handicapped. I could motivate them to do something with the abilities they have left, or encourage them to overcome what they see as insurmountable obstacles. Or, who knows, I may find my niche in some area that I haven't even dreamed of yet. I do know that my chances of finding work in Birmingham or some other metropolitan area are much greater than they are in rural Alabama.

MOTHER'S EMOTIONAL DEPENDENCY ON ME

The older she gets, the more Mother makes me the center of her life--putting me ahead of her husband, her other son, and her grandsons. Daddy wants and needs more of her attention, so I have become a constant source of friction between them. Mother doesn't have as many outside activities as other women her age, and I'm her reason and excuse. As either a cause or a result of this emotional dependency, she still perceives me as a child for whom all major decisions must be made. (A major decision is anything concerning money, or movement outside my room.) Mother sees any attempt on my part to become more independent as a sign of ingratitude for the sacrifices she has made. For example, the time I took control of my own checking account, Mother literally could not sleep at night until she had that power back in her hands. She saw the loss of control as a threat to her authority. She reminded me over and over again that no one else had ever taken care of me, and she had done it even when she was so sick that she had to crawl on the floor to get to my bed. Mother says she does these things because she loves me, but they do not make me feel loved; they make me feel possessed.

When I first got sick, instead of placing me in a childrens' hospital, Mother and Daddy decided to take care of me at home whatever the cost, and the cost was high. For the first ten years, my drug bill was so high that Daddy was constantly borrowing money to keep the family afloat. There was no money for luxuries, and finding money even for the necessities of life was a constant struggle. Since then, the financial burden has gone away, but the psychological and physical burden of caring for me has continued. It has been 27 years since my parents knew what it was like to be free. For 27 years, I have heard exchanges like this: A friend of my parents will say, "Why don't y'all come to visit?" Invariably, Mother or Daddy will answer, "Well, we'd like to, but with Daryl sick here the way he is, we never go anywhere." This is the same reason given for not going to church, out to eat, and the list goes on and on. When Mother and Daddy do leave home together, either I go with them or they find someone to sit with me. Finding a sitter is not easy, so usually, they decide the trip was not necessary after all, or one will go while the other stays with me.

THE NEED FOR LOVE AND PHYSICAL AFFECTION

I have the same feelings, needs, and desires as any other man. I very much want to find a woman to share love with. There is a woman in my life now, but living at home has made it difficult to build a good relationship. My parents do not respect the privacy of my room; they open the door and walk in when they please. And of course, I couldn't expect them to leave their own house for me to be alone with a date. On the other hand, I'm not allowed to leave the house even for a few hours without my mother's permission, which is never given unless she approves of the people I'm going to be with. Even then, her permission is capricious. Then, there's the problem of a mother's jealousy. If I show too much interest in a woman, Mother says things like, "She's fat and has stringy hair," or "That girl is skinny and dresses like a slob." Or worst of all, when an attractive woman shows too much interest in me, "She's just being nice. Why would a girl like that be interested in *you*?"

At home, my parents are responsible for my physical care. Seeing this situation, any woman would think, and logically so, that if she became involved in a long-term relationship with me, she would be expected by my parents to take on much of this responsibility. However, if I were living in a different environment with paid attendants taking care of me, a potential lover could feel less threatened. Of course I don't expect to find the love of my life simply by leaving home, but becoming more independent would remove many obstacles.

In spite of the fact that I'm a legal adult, my parents are still opposed to my leaving home. I must either go against their wishes and make a new life for myself (and allow them to do the same), or stay here feeling like an anchor dragging us all down.

TODAY'S FANTASY WORLD

In my daydreams now, I'm living in a larger town. Often, friends come over and we sit around listening to the stereo and drinking coke. Now and then, we go to a concert, or just outside, under the trees. It's good to be anywhere with friends.

EPILOGUE

Since writing this paper as a special project in Psychology at UAH, Daryl Smith has not only gotten his Bachelor's degree, but has also gone on to get a Master's degree in Counseling Psychology. He is currently doing telephone survey work for Huntsville Hospital, which entails phoning recently dismissed patients to evaluate their satisfaction with the care they received while at the hospital. Daryl still lives in Moulton, Alabama with his parents. This story is not finished.

STATEMENT BY F. ANN COPE

My name is F. Ann Cope and I live in Media, Pennsylvania, a suburb of Philadelphia. I am thirty-five and have been orthopedically disabled all of my life. I began my education in a special class developed by the Delaware County Board of School Directors that grew into a six classroom school years before P.L. 94-142, the Right to Education Act, was passed. I was later mainstreamed into my local high school and then earned a Bachelor's Degree from The Pennsylvania State University. I now own my own business and work as a part-time Public Relations/Outreach consultant for a non-residential Center for Independent Living.

In my testimony, I would like to use examples from my own life to illustrate the need for adaptive equipment, its distribution and especially an information network to let the disabled consumer know what is available. I cannot overemphasize the need for such a network. If nothing else comes out of the subcommittee's effort, making every consumer across the nation aware of every product that is available is of extreme importance and a major task in itself.

EXAMPLE: Ten years ago, I was evaluated by a driving instructor as needing a highly sophisticated driving system and lift installed in a van, due to my severe, orthopedic disability. The Scott van was recommended to me, developed by a person in Southern California, but no one knew how to put me in touch with him. Even while visiting California the following summer, I was unable to determine his whereabouts, despite numerous inquiries in the Southern California area. I have only been able to track down this specialized van in the last year, and have missed out on over ten years of driving time -- the freedom to come and go at will.

In regard to this, there must be a reduction in territorialism, both geographic and among service providers, to make such a system work properly. In other words, equipment available in California must be made known to consumers across the country, and it must be made available to them as well. A consumer, or the professional working with him or her, cannot determine what piece of equipment best suits the consumer's particular needs, if the choices are limited by the service provider's geographic location or product line.

EXAMPLE: When I was young, my parents found no suitable provider in Pennsylvania to equip me with the devices appropriate for my special needs. Thanks to the insurance coverage provided through my father's job, I was able to receive the therapy and devices I needed in New York. But now that I am an adult and must depend on my state's vocational rehabilitation system, I am limited by the bidding process which is, many times, restricted to service providers within Pennsylvania. Although there are many qualified providers in the state today, the bidding process itself, is restrictive.

Another problem with the current system is follow-up service. Once the bids have gone out and the contract has been awarded, the consumer is "at the mercy" of the awardee to be outfitted/served properly. In many situations, the consumer's case file has to be reopened every time a new device -- even the most simple ones -- is needed. And this means having to go through the entire application and approval process all over again.

It has been suggested that the Information/Service system that could be set up as a result of the subcommittee hearing may be regional, encompassing more than one state; the system could be segmented by the disabilities being served; or the money could be allocated to the individual states to be distributed as each sees fit.

My strongest objection is to the latter. States that presently have strong and flexible Information/Service Delivery systems will continue to operate in this fashion. However, those states whose systems leave much to be desired by the consumer probably will continue to deliver weak and inadequate service no matter how much money is given to them by the federal government.

At the least, there must be a strong set of guidelines that the states must follow should they be in charge of dispersing the monies, information and services, themselves. Disabled consumers as well as the professionals should be aware of these guidelines and the correct methods of recourse if they feel that they are not being appropriately served.

Segmenting the service delivery system by disability has the distinct disadvantage of leaving gaps of unserved disabled consumers. Since some people, such as myself, do not fit into a specific disability category, their needs may continue to be overlooked by the larger, more complicated service organization network.

Some of the largest gaps that exist in the current systems are in the areas of age, vocation, education, disability and rehabilitation. Services and devices available through some special education programs are not available after the student leaves the system; those not deemed employable may not be covered by existing rehabilitation programs; until recently, many services available to elderly persons with disabilities, or children, were not available to people between the ages of eighteen and fifty-nine; and persons, like myself, who do not receive ongoing therapy or medical treatment for a disability have no direct link to the variety of products and services that are available.

Ideally, the new Information/Service Delivery system should include established organizations that have already proven themselves to be successful in their fields, supplemented by new organizations that will encompass the weak or neglected areas of service. If, for instance, one state has excelled in the area of special education and related devices (such as Pennsylvania's Special Education Resource Center), it should administer a similar program throughout the region in which it falls. If another state in that region has developed an excellent rehabilitation program, it should administer that segment of the program. (If each state will be working independently, the same process of a proven organization administering each phase of the program should apply on a statewide level.)

By using the systems that are already in place, the government will:

-- save money in start-up and training costs that could be put to better use directly serving the consumer,

-- strengthen the organizations and systems that already exist, rather than setting up new ones to compete for the same funding and consumers, and

-- do away with some of the bureaucracy and "red tape" so often associated with government projects.

Regional service areas would help to advert the previously mentioned concern that states with strong programs will continue to excel while those with already weak programs will continue to leave he consumer inadequately served. However, if it is finally decided that the program will be administered within each state, guidelines and new agencies/organizations should be put in place by the federal government to assure that comparable services are being provided to all disabled consumers no matter where they reside.

It is extremely important that the Information and Referral segment of the project is a strong, nationwide network, so gaps are not created between states or regions. It is also important that it is directly accessible to the consumer and marketed that way, so that consumers, like myself, with no affiliation to any specific disability, rehabilitation service or hospital would have direct access to it.

Following the premise that it is best to use established organizations or services whenever possible, I would recommend that Centers for Independent Living be utilized. They are already a nationwide network with established Information and Referral systems that serve the general disabled population with the goal of helping them to live independently.

In conclusion, I would like to say that there is a definite need for devices of all types to make the goal of independent living and productivity a reality for each individual with disabilities. Communication systems, similar to the mobile cellular telephone so that a person in a wheelchair can move about and still have a safety link in an emergency situation, wheelchairs that raise and lower so that persons of all heights can use the same tables and counters, and numerous other technological devices still need to be developed. But in this day of high-technology, do not forget that sometimes a simple device is all that is needed to give some people their independence . . . a gadget to hold a pot or pan while stirring, a can opener that can be operated with one hand, or a knife with a bent handle.

While focusing on the many devices that are needed to help all people with disabilities reach their full potential, remember that the real goal is to eventually wipe out disability altogether. Money and effort must continue to aid research to find the causes and correct the disabilities that do exist. In the meantime, let s not forget that the accent should always be on abilities!

A Proposed Demonstration of Technology Assistance As It Applies to A Training Program for Disabled Veterans.

Testimony
to the Subcommittee on the Handicapped
of the Committee on Labor and Human Resources
of the U.S. Senate

May 24, 1988

Eugenie (Jolie) Mason
Proposal Manager/Principal Investigator.
Defense Systems Dept., System Development Group
UNISYS CORP.

I am Jolie Mason, proposal manager and principal investigator for the Ada and the Disabled Veterans Proposal. I am interested in training disabled veterans in Ada, a computer language. It is obvious that there is a significant interest in using computer technology to overcome the handicap of a physical disability. As a blind computer analyst the host of computer gadgets I use certainly makes my day-to-day living easier. However, I am not just interested in expanding the use of computers by the handicapped, I am also involved in facilitating more handicapped programmers. I am an employee of Unisys, and I am proposing a training project which would involve IBM, Digital Equipment Corporation, along with Unisys in training disabled veterans to program in Ada. Ada is a computer language specifically developed for military and other Government applications.

How did all this start?

I spoke at the Ada Expo, conference on Ada and the Handicapped. As a result of this presentation I met Bill Easton, who volunteered to read the Military Standard and other related Ada material. Dr. Easton is now a volunteer reader at the Washington, D. C. Recording for the Blind office. (RFB) He has taught at Princeton, Cornell and Rutgers Universities and has outstanding qualifications for this task. He is active and well-known in the Ada community, with over 30 years of experience in the computer field, including conversion of other computer systems into Ada. However, there still is the problem of distributing the recorded material to the blind veterans participating in this project. My suggestion is to have each participant apply to become a RFB user. This means that the recording will have to have national access so it can be ordered as needed. The reason I have gone into this in such great detail is because it illustrates two of the essential elements that are required to obtain the maximum benefit that assisting technology can provide. They are: use existing organizations and experiences as input to new ideas; give the widest possible exposure to the ongoing results of this process.

This first idea, build on success to achieve greater success, is why I look at adaptive technology from another point of view. Instead of adapting a piece of equipment so that it can be used in some situations, innovative uses of standard equipment can allow it to be adapted for use in many situations. Rather than looking at adaptive technology as electronic modifications to a piece of equipment, adaptive technology can also represent additional uses of devices or methods. Some examples: I have a colorbook originally put out so that people can match the colors they wear to their skin coloring. However, I can use that book when I am shopping to ensure that what I buy will match the clothes in my closet. It allows a sales person to know the colors I need of the item I want to buy as well as giving me a set of color names to use in sighted/non sighted discussions.

I have a light sensor, originally developed to tell when a light was on or off, that light sensor can also be used to tell the difference between colors by a change in pitch. It can be used to identify a black line to a white background or to trace a dark shape against a light page. It is true that lots of people use key-finders to locate where they put down their keys. I can use a key-finder to locate where my backdoor is when I am running to answer the phone, when I am outdoors gardening.

A Vox-Com is a device that plays back a recorded card. It is intended for use in labeling food containers. However I use these cards when I am organizing text. They allow me to edit what I am writing because I can change the order of the information, add additional cards when I want to expand on a topic or delete cards to summarize major elements. This is hard to do with a dictaphone tape.

Again, all of these are adaptive uses in the function of the equipment. I think this idea is important. Those additional uses of equipment were developed because I was using the equipment often. What is essential is accessibility. Only then can novel uses for items be discovered by creative users.

All of these things, electronic modifications or innovative ideas, are adaptive uses of technology and I think it is important to keep track of them. Simply displaying a lot of very nice, flashy, expensive assistive gadgets on tables at some technology center is interesting, but, far more important is to see these things being used in a comprehensive environment.

If one picture is worth a thousand words, one success is worth a thousand failures. Work hard to accomplish a success. Only then can that success be copied or modified to make sure it achieves even more. Rather than saying, "how can this be done?" look at how similar things have been done successfully before. Success is magnetic. To try something new is to put one at risk, to succeed relieves all anxiety. This is why people are eager to associate themselves with a venture, once it is successful.

How well are we doing on building on the foundation of our current successes? There is a tremendous amount of wasted information, inventions, skills and experience because of disorganization. There is also a tremendous amount of duplicated information, while some facts never get disseminated outside of an originating group. There is little traceability regarding how a piece of assistive technology has been developed or used. There needs to be more communication and coordination. At this point, a news program is better than a new program.

For example, when you talk about jobs for the handicapped, the general public is almost completely unaware that sufficient adapting technology exists to enable almost any handicapped person to overcome the physical limitations of a work environment I am a handicapped person and I have suffered because ofthis lack of understanding. Although I have worked for the same company, I have worked on numerous projects throughout my career. Each project I go to is very similar in many ways to joining a different company. Each requires a different set of equipment. I have to assert that I can figure out how to adapt my devices and methods to that particular situation while no such guarantee can be made. The equipment is very expensive. It isn't very reasonable to expect an employer to invest in that equipment for me before I have produced any profitable output. Yet to be able to function in that enviroment means there is a catch-22: I must already have the equipment to be able to work in that environment, so that I can convince people that I will be able to work in that environment.

The question that I am almost always asked at any job interview despite all of the achievements documented through my resume and references is, "how do you do your work?" A sighted person is rarely asked on a job interview, "how do you get to work?" (But I am). They are asked instead about the qualifications for the job. Questions about equipment and transportation are understandable because of the lack of widespread information about how the handicapped work. It turns out that the handicapped make excellent employees: with longer company commitments, a higher tolerance regarding frustration levels, and a geniune desire to contribute. Instead of knowing this employers are asked to have faith in methods and products that haven't been demonstrated. It seems to me that if there wer a means that integrated all of these different aspects it would actually demonstrate to people how it is possible for the handicapped to work, by people I nean not just administrators, managers, employers, and potential employees but even junior high school kids and younger children. Just believing that the handicapped can indeed get a job will make a difference throughout a person's entire life. This is why I believe that even a small project is needed to actually demonstrate how all of this cycle interacts from beginning to end. Only by showing that indeed a group of people who are disabled can apply adaptive equipment to a real work type environment, will people be convinced that it is not such a risk to hire the handicapped. I do not think it is most efficient to cncentrate major effort on new methods, nor do I think there have to be huge sources of funding. What I do think is essential is coordination and participation.

The training program I represent proposes to teach the use of adaptive technology along with work skills, specifically the computer language Ada to disabled veterans. This is not a new idea, however, it is based on successful precedent. I was a student of a computer programming class for the blind that was taught at my company.

There is a lot of interest in participation in such a project. Sponsoring corporations have assured that their equipment would be available to these candidates. UCLA has agreed to provide classroom facilities. There are already programs in the Veterans Administrations that could assist with tuition. Instructors are available as well as interested students. All that is needed to crystallize these plans into a reality are resources for a technology center. Disabled veterans did not start out as veterans or disabled. They made a contribution. It is time to make a contribution back.

Senator **Harkin**. The subcommittee will stand adjourned.

[Whereupon, at 11:34 a.m., the subcommittee adjourned, subject to the call of the Chair.]

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